

**EXPLORING THE COMPLEXITY OF THE PRIMARY HEALTH CARE TRANSITION
OF YOUTH AND YOUNG ADULTS WITH CEREBRAL PALSY LIVING IN SAULT
STE. MARIE, ONTARIO: A MIXED METHODS STUDY**

By

CHELSEA L. SEGUIN

Thesis submitted in partial fulfillment of the requirements for the degree of
Master of Science (M.Sc.) in Interdisciplinary Human Development

School of Graduate Studies
Laurentian University
Sudbury, Ontario

© Chelsea Seguin, 2013

THESIS DEFENCE COMMITTEE/COMITÉ DE SOUTENANCE DE THÈSE

Laurentian University/Université Laurentienne School of Graduate Studies/École des études supérieures

Title of Thesis
Titre de la thèse

EXPLORING THE COMPLEXITY OF THE PRIMARY HEALTH CARE
TRANSITION OF YOUTH AND YOUNG ADULTS WITH CEREBRAL PALSY
LIVING IN SAULT STE. MARIE, ONTARIO: A MIXED METHODS STUDY

Name of Candidate
Nom du candidat

Seguin, Chelsea L.

Degree
Diplôme

Master of Science

Department/Program

Date of Defence

Département/Programme Interdisciplinary Human Development Date de la soutenance November 15, 2013

APPROVED/APPROUVÉ

Thesis Examiners/Examineurs de thèse:

Dr. Nicole Yantzi
(Supervisor/Directrice de thèse)

Dr. Shelley Watson
(Committee member/Membre du comité)

Dr. Nancy Young
(Committee member/Membre du comité)

Prof. Debra Stewart
(External Examiner/Examinatrice externe)

Approved for the School of Graduate Studies
Approuvé pour l'École des études supérieures
Dr. David Lesbarrères
M. David Lesbarrères
Director, School of Graduate Studies
Directeur, École des études supérieures

ACCESSIBILITY CLAUSE AND PERMISSION TO USE

I, **Chelsea L. Seguin**, hereby grant to Laurentian University and/or its agents the non-exclusive license to archive and make accessible my thesis, dissertation, or project report in whole or in part in all forms of media, now or for the duration of my copyright ownership. I retain all other ownership rights to the copyright of the thesis, dissertation or project report. I also reserve the right to use in future works (such as articles or books) all or part of this thesis, dissertation, or project report. I further agree that permission for copying of this thesis in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis work or, in their absence, by the Head of the Department in which my thesis work was done. It is understood that any copying or publication or use of this thesis or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that this copy is being made available in this form by the authority of the copyright owner solely for the purpose of private study and research and may not be copied or reproduced except as permitted by the copyright laws without written authority from the copyright owner.

Abstract

EXPLORING THE COMPLEXITY OF THE PRIMARY HEALTH CARE TRANSITION OF YOUTH AND YOUNG ADULTS WITH CEREBRAL PALSY LIVING IN SAULT STE. MARIE, ONTARIO: A MIXED METHODS STUDY

Masters of Science, 2013

Chelsea L. Seguin

Laurentian University

The vast majority of children with cerebral palsy (CP) are surviving into adulthood due to improved surgical and health care practice. Thus, the expiration of paediatric services means that a new population of adults with CP has emerged that must transition into an ill-equipped adult-oriented system. Informed by the perspective of complexity theory, this case study used both quantitative and qualitative data to examine the primary healthcare transition of youth with CP living in Sault Ste. Marie, Ontario. Analysis of Ontario Health Insurance Program claims showed service use changes due to both the expiration of paediatric services and the changing health needs of individuals with CP as they age. Physicians commented on challenges due to the complexity of the CP disease process and the benefits of shared care and teamwork in discussing transition. Future research and clinical practice designed to address transition barriers need to be informed by complexity theory.

Acknowledgements

First and foremost, I would like to thank my master's thesis supervisor, Dr. Nicole Yantzi. I am extremely grateful for your continuous academic guidance and emotional support. Through each and every obstacle (and there were many!) that arose during the writing of this thesis, you motivated me to persevere and to always see the positive outcomes. You have taught me to recognize my abilities and be confident in my research. Your supervision has been more than academic guidance; with your support I have discovered more about myself than I could have imagined throughout this master's. Thank you to my advisory committee members, Dr. Shelley Watson and Dr. Nancy Young. Your diverse backgrounds and extensive experience have contributed to the complexity of this thesis. Thank you for your continuous support, contributions and academic guidance.

Thank you the physicians of Sault Ste. Marie who participated in this study. Your opinions and discussions are invaluable. I would also like to express my gratitude to the Canadian Institute of Health Research, by which my master's education was partially funded through the achievement of the CIHR Frederick Banting and Charles Best Master's Award.

On a personal note, I would like to thank my parents Carrie and Wade Seguin. If it weren't for your support and encouragement, I wouldn't be where I am today. You've provided me with so much opportunity and I am eternally grateful for all you have done for me. I love you both. To my wonderful boyfriend, Kevin, I am so thankful to have you in my life. You motivate me every day to better myself and push my limits. I love you for all that you are.

This thesis is dedicated to those who search for answers to their questions and strive to make a difference. In the words of Mahatma Gandhi, "Be the change you wish to see in the world".

Table of Contents

Abstract.....	iii
Acknowledgements.....	iv
Table of Contents	v
List of Abbreviations	vii
List of Tables	viii
List of Figures.....	ix
List of Appendices.....	x
Chapter 1: Introduction and Review of the Literature.....	1
1.1. Introduction.....	1
1.2. Cerebral Palsy: A Background	3
1.3. Primary Care of Patients with Cerebral Palsy.....	10
1.3.1. Additional Barriers and Challenges	14
1.4. Healthcare Transition	15
1.4.1. Shared Management Model.....	19
1.5. Changing Face of Family Medicine in Ontario: Providing a Medical Home	22
1.5.1. Section of Family Physicians with Special Interests or Focused Practice	25
1.6. Context of Primary Care in Sault Ste. Marie	27
1.6.1. The Algoma District Medical Group/Group Health Centre.....	31
1.6.2. Superior Family Health Team & Baawaating Family Health Team	32
1.7. Systems Thinking and Complexity Theory as a Foundation for a Study on Healthcare Transition	32
1.8. Chapter Summary	35
1.9. Research Questions.....	36
Chapter 2: Research Design	38
2.1. Chapter Introduction.....	38
2.2. Use of Case Study and Complexity Theory in the Research Design.....	39

2.3.	Quantitative Data: Claims History Database – Ontario Health Insurance Program (OHIP) Fee-for-Service Claims	40
2.4.	Qualitative Data: Physician Interviews	43
2.5.	Chapter Summary	48
Chapter 3:	Findings	49
3.1.	Chapter Introduction	49
3.2.	OHIP Claims History Data.....	49
3.2.1.	Descriptive Statistics: Person Dimension.....	50
3.2.2.	Descriptive Statistics: Place Dimension	51
3.2.3.	Service Utilization of Medical Specialties by Patient Age Group	52
3.2.4.	Summary of Findings from OHIP Claims: Person and Place Dimensions.....	58
3.3.	Interviews.....	59
3.3.1.	The Complex Nature of Healthcare Transition	60
3.3.2.	Shared Care and Teamwork	65
3.3.3.	Physician Tools and Resources	71
3.3.4.	Summary of Interviews	78
3.4.	Chapter Summary	80
Chapter 4:	Discussion and Conclusions.....	82
4.1.	Discussion.....	82
4.1.1.	Utilization of Medical Specialist Services Across Age Groups	83
4.1.2.	Challenges and Barriers of Healthcare Transition	85
4.1.3.	Innovative Solutions for a Brighter Future.....	89
4.2.	Linkages and Contribution to the Literature.....	90
4.2.1.	Transition Models.....	91
4.2.2.	Complexity Theory and Healthcare	92
4.3.	Limitations	93
4.4.	Implications and Considerations for Future Research and Clinical Change.....	96
4.5.	Dissemination and Knowledge Translation	98
4.6.	Conclusion	99
References.....		103
Appendices.....		119

List of Abbreviations

CFPC	College of Family Physicians of Canada
CHC	Community Health Centre
CP	Cerebral Palsy
CPS	Canadian Paediatric Society
FHG	Family Health Group
FHN	Family Health Network
FHT	Family Health Team
FSA	Forward Sortation Area (first three digits of Postal Code)
GERD	Gastroesophageal Reflux Disorder
GMFCS	Gross Motor Function Classification System
LHIN	Local Health Integration Network
MCHB	Maternal and Child Health Bureau
MOHLTC	Ministry of Health and Long-Term Care
OHIP	Ontario Health Insurance Program
OTN	Ontario Telehealth Network
SAHM	Society of Adolescent Health and Medicine
SIFP	Special Interest and Focused Practice

List of Tables

Table 1. Distribution of Sault Ste. Marie Family Physicians and Paediatricians by Primary Practice Location.....	31
Table 2. Data Requested from MOHLTC OHIP Claims Database.....	42
Table 3. Top 10 Most Frequently Used Words	47
Table 4. Example of Initial Coding Process of Physician Interview Transcripts	47
Table 5. Average Age and Number of Claims per 1000 Individuals with CP Submitted for each of the Paediatric and Transition Age Groups.....	51
Table 6. Percent (%) of Total Claims Submitted by Medical Specialty.....	51
Table 7. Percent of Total Claims of all Medical Specialties by LHIN of Primary Practice Location.....	52
Table 8. Top Ten Medical Specialties with Claims for the Paediatric Age Group.....	53
Table 9. Top 10 Medical Specialties with Claims for the Transition Age Group.....	53
Table 10. Themes and Sub-themes for Physician Interviews	60

List of Figures

Figure 1. The Shared Management Model.....	20
Figure 2. The Local Health Integration Networks (LHINs) of Ontario.....	29
Figure 3. Extensions of Case Study Design Using a Complexity Science Blueprint.....	40
Figure 4. Medical Specialist Service Use by Location for Paediatric Age Group.....	55
Figure 5. Medical Specialist Service Use by Location for Transition Age Group	55
Figure 6. Percentage of Claims from 'Other Medical Specialists' by Location for the Paediatric Age Group	57
Figure 7. Percentage of Claims from 'Other Medical Specialists' by Location for the Transition Age Group	57

List of Appendices

Appendix A: Ethics Certification - Laurentian University Research Ethics Board	119
Appendix B: Ethics Certification - Joint Group Health Centre/Sault Area Hospital	120
Appendix C: Ministry of Health and Long Term Care: Data Application Form - Data Element Request	121
Appendix D: Sensitivity Analysis	122
Appendix E: Dear Doctor Letter.....	123
Appendix F: Reminder Cards	124
Appendix G: Informed Consent Forms (Main and Supplementary).....	125
Appendix H: Semi-Structured Interview Script.....	127

Chapter 1: Introduction and Review of the Literature

1.1. Introduction

The worldwide prevalence of cerebral palsy (CP) in developed countries is not substantially declining, despite the many changes in the management of pregnancy and prevention of pre-term labour in recent decades (Iams, Romero, Culhane, & Goldenberg, 2008; O'Shea, 2008).

Population-based studies worldwide have reported that approximately 1.5 per 1000 live births result in the infant acquiring CP (Paneth, Hong, & Korzeniewski, 2006). The registry data from the United States and Canada are sparse, and of the research conducted in these countries the prevalence of CP has been documented at rates as high as 3.3 per 1,000 individuals (Arneson, et al., 2009). Studies with higher prevalence rates have been criticized for being inflated by inconsistent denominators (Paneth, Hong, & Korzeniewski, 2006). Some epidemiologists feel that birth place should not be ignored when calculating prevalence and incidence rates, as it may be influenced by the movement of families of children with CP to areas with more specialized medical care facilities (Paneth, Hong, & Korzeniewski, 2006).

Advances in medical and surgical management of CP have led to a longer life-expectancy resulting in about 90% of children with CP living well into adulthood (Hemming, Hutton, & Pharoah, 2006). As a result, a new population of young adults with CP has emerged that must transition from the paediatric circle of care to an adult-oriented system that may not be prepared to provide the necessary medical and supportive services (Young, 2007). Healthcare providers will therefore need to address the needs of adults with CP as today's children age into adulthood.

The challenges faced by young adults¹ with childhood-onset disabilities, such as CP, as they move from the paediatric to adult health care system have sparked research and development of transition programs at various facilities across Canada. However, the concept of health care transition has consequently encountered numerous obstacles in practically implementing quality care within the adult system, including the inability of paediatricians to “let go” of their patients (Binks, Barden, Burke, & Young, 2007; Fox, 2002; Reiss, Gibson, & Walker, 2005). Obstacles also include a general lack of knowledge and experience in the adult system in regards to caring for people with CP (McDonagh, 2005). Additionally, the simple transfer of care has been challenged in the past 20 years by the notion of ‘transition’, emphasizing the “need for the change to adult care to be a guided educational therapeutic process rather than an administrative event” (Viner, 1999, p. 271).

To set the foundation for the exploration of the research questions, pertinent areas of literature were explored, including information pertaining to the diagnosis of CP and the wide spectrum of medical issues across the lifespan, the concept of healthcare transition, healthcare in Ontario, as well as literature describing complexity theory in terms of healthcare systems. Articles and information from both published, peer-reviewed journals and various sources of grey literature were reviewed. For the purposes of this thesis, grey literature refers to various government regulated and health organization websites and reports. It was important to include the grey literature as it is updated regularly and is most likely to include the newest opinions and practices from within the rapidly changing healthcare system. Using various sources of literature provides a broader perspective to healthcare transition for young adults with childhood onset

¹ Young adult is the term used throughout this document to describe a sub-set of people older than childhood, but younger than adults. Young adults will fall between the ages of 17-21, and in the analysis portion of this research will be considered the “transition age group”.

conditions, such as CP. This literature forms the foundation for the proposed research, which focuses on the changes in medical service utilization as youth with CP age, as well as barriers to transitioning youth with CP to adult healthcare, and possible solutions to closing the transition gap, from a perspective of complexity theory.

1.2. Cerebral Palsy: A Background

Cerebral palsy (CP) is the most common physical disability of childhood onset worldwide with a prevalence of about 3.3 per 1000 live births (Arneson et al., 2009). CP is a result of damage to the immature brain and is defined as:

A group of permanent disorders of the development of movement and posture, causing activity limitations, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain ... [and] are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems. (Rosenbaum, Paneth, Leviton, Goldstein, & Bax, 2007, p. 8)

There is a higher risk of intellectual disability among persons with CP than in the general population. Between 23 and 44% of children with CP have an IQ <70 (Cans, 2000), but it is important to note that not all children with CP have cognitive impairments.

The signs of CP (except in its mildest forms) usually become obvious as early as 6 to 18 months of age (Rosenbaum, 2003). Babies with CP are slow to reach their developmental milestones, such as rolling over, sitting up, crawling and walking. CP varies widely in its severity (Rosenbaum, 2003). In its mildest form, it manifests in a slight awkwardness of movement or hand control; in its most severe form, there may be virtually no muscle control and profoundly compromised movement and speech (Jones, Morgan, & Shelton, 2007). The current

definition of CP covers a wide range of clinical presentations and degrees of activity limitation. Therefore, it is useful to further categorize individuals with CP into classes or groups.

Traditional classification of CP groups has focused on the distribution pattern of affected limbs (e.g. hemiplegia, diplegia) with an added modifier describing the predominant type of muscle tone or movement abnormality (e.g. spastic, dyskinetic). Rosenbaum et al. (2007) suggest that in classifying severity of CP, documentation should include the age of the child, the nature of the information available from clinical history, and the extent to which metabolic and neuroimaging investigation has been performed. Classification often requires making difficult decisions about where to draw the boundaries within ordinal or quantitative measures. Assignment of individuals with a diagnosis of CP to distinct clinical groups will differ depending on the characteristics chosen as the basis for classification. While by definition the neurological lesion responsible for CP is not progressive, the disturbances of movement that result often change as a function of growth and development. Thus, a period of observation that includes serial examinations of the child may be needed before severity classification.

Functional severity of CP is classified using the Gross Motor Function Classification System (GMFCS), which assigns a level of gross motor function from Level I to V (Russel et al., 1989). Palisano et al. (1997) extended the GMFCS specifically for use with people who have CP. The GMFCS has been rapidly accepted into clinical practice and research (Morris & Bartlett, 2004). The GMFCS for CP is based on self-initiated movement with particular emphasis on sitting (trunk control) and walking. Distinctions between levels of motor function are based on functional limitations, the need for assistive technology, including mobility devices (e.g., walkers, crutches, and canes) and wheeled mobility, and the quality of movement (Palisano et al., 1997). Level I includes children with neuromotor impairments whose functional limitations

are less than what is typically associated with CP, and children who have traditionally been diagnosed as having ‘minimal brain dysfunction’ or ‘cerebral palsy of minimal severity’ (Palisano et al., 1997). On the severe end of the GMFCS scale, children in Level V lack independence even in basic antigravity postural control (i.e., use of muscles that involuntarily work against gravity; postural muscles). Their self-mobility is achieved only if the child can learn how to operate an electrically powered wheelchair (Palisano et al., 1997).

The impact of CP on a child’s participation in activities depends on the severity of impairment, as well as environmental and personal conditions, which is richly described by the Person-Environment-Occupation (PEO) Model of occupational performance (Law et al., 1996). It is important to consider a person’s activity level in the context of their own environment, and goals relating to the development of independence are within this context. A study describing the use of the PEO model in occupational therapy indicates that the model can be used as a tool for therapists to use in developing client-therapist relationship to enable clients to successfully engage in meaningful occupations in chosen environments (Strong, Rigby, Stewart, Law, Letts, & Cooper, 1999). The importance of environmental consideration for participation of people with complex disabilities is also recognized by the International Classification of Functioning, Disability and Health (ICF), a framework for measuring health and disability developed by the World Health Organization (2001). The ICF shifts the focus of disability from cause to impact, and takes into account the social aspects of disability. The ICF includes contextual factors, in which environmental factors are listed allowing the tool to record the impact of environment on an individual’s functioning.

People living with the more severe forms of CP may require the use of extensive services and environmental supports, such as personal care, ongoing therapies, or assistive devices for

mobility (Rosenbaum, 2003). Children with CP frequently require specialized medical, educational, and social services. These needs will extend and ultimately expand as children age and become more independent in the management of their disability, and must be considered in the context of their environments and the impact the environment has on their functioning.

There are a number of general and specific health issues that are relevant to both children and adults who have CP. Health problems may not always be immediately obvious. They include increased vulnerability to a variety of infections, including those of the respiratory system and urinary tract (Rosenbaum & Rosenbloom, 2012). Other problems that should be kept in mind by health professionals are the issues concerning respiratory function, nutritional status and its maintenance, the management of drooling, bone density issues, the treatment of epilepsy, medical interventions used to manage spasticity, dystonia and involuntary movements, degenerative joint changes and the cervical myelopathy that may be seen in athetoid CP (Rosenbaum & Rosenbloom, 2012). In addition, there is a significant and important role for orthopaedic surgery as a component of multi-professional therapeutic interventions in CP (Aisen et al., 2011).

Depending on the nature and extent of the neurological impairments, people with CP of all ages can demonstrate the whole range of health problems that may be seen in the general population, together with some specific issues that are more likely to occur because of, and in association with, the individual having CP (Rosenbaum & Rosenbloom, 2012). The most important of these issues relates to growth and nutrition (Day et al., 2007). Both as a direct consequence of brain damage and also mediated by other oromotor and digestive issues such as dietary, feeding, and swallowing, children with CP commonly demonstrate varying degrees of nutritional failure (Krick & Van Duyn, 1984; Waterman, Koltai, Downey, & Cacace, 1992).

Virtually all physiological functions are adversely affected by suboptimal nutrition. Prominent effects include muscle weakness, including weakness of respiratory muscles and hence an enhanced predisposition to chest infections (Rosenbaum & Rosenbloom, 2012). These effects may also be made more likely by a risk of aspiration of food associated with poor oromotor control (including swallowing), and by the reduced immunological competence that can be a consequence of impaired nutrition (Sullivan, Lambert, Rose, Ford-Adams, & Johnson, 2000). It may also be that improved nutrition promotes a child's general well-being and alertness and provides an appropriate platform for developmental progress to be made (Gramtham-McGregor, Powell, Walker, & Himes, 1991; Sanders et al., 1990; Stallings, Charney, Davies, & Cronk, 1993; Stoch, Smyth, Moodie, & Bradshaw, 1982). In a study by Sullivan et al. (2000) it was noted that more than 64% of the children in the study had not previously received a detailed assessment of their eating, drinking, and nutritional status.

In addition to the biological implications of impaired feeding and poor nutrition, the psychosocial aspects of impaired feeding in children and youth with significant disabilities merit consideration. The commitment of parents, especially mothers, to oral feeding can be very strong, sometimes even when there is evidence of very prolonged mealtimes, nutritional failure, signs of aspiration, and symptomatic gastro esophageal reflux disorder or GERD (Reilly, Skuse, & Poplete, 1996). Careful and sympathetic multidisciplinary assessments and reviews may be required over long periods of time before definitive treatment plans, such as gastrostomy tube, are implemented (Katz, 2003). It is important to remember as well that from youth through to late adulthood, difficulties with eating and drinking can present as a significant challenge to social acceptance (Rosenbaum & Rosenbloom, 2012).

In addition to the multitude of physiological and psychosocial issues related to growth and nutrition, the prevalence of epilepsy (i.e., recurrent seizures) is much higher in people with CP and other neurological disabilities than in the general population. Epilepsy occurs in about 3 to 6 per 1000 people in the general population (Forsgren, 1996). Overall, epilepsy occurs in up to one third of children and adults with CP (Kirby et al., 2011) and is more common in some classifications of CP than others (Hadjipanayis, Hadjichristodoulou, & Youroukos, 1997). Epilepsy in CP is secondary, that is to say it is symptomatic and occurs as a consequence of the brain damage that initially caused the motor disorder and other impairments (Rosenbaum & Rosenbloom, 2012). For the large majority of people with CP who have epilepsy, their seizure disorder is not especially intrusive and may consist of relatively brief and infrequent episodes that, if need be, can be kept under control with appropriate anticonvulsant therapy (Rosenbaum & Rosenbloom, 2012). However, if seizure management is not closely monitored throughout the lifespan, epilepsy will become a major health issue for youth and adults with CP and may contribute to increased pain and fatigue in adulthood (Hilberink et al., 2007).

It is of interest that there are few reports detailing mental health disorders in adults with CP. Nevertheless, paediatric clinical experience, together with evidence of increased mental health vulnerability in populations with brain injury (Mortimer et al, 1985), make the existence of a whole range of mental health disorders highly probable in adults with CP. In a study describing the reasons for hospital admission of youth and adults with CP, Young et al. (2011) found several common reasons for admission that were not evident in the literature, including mental health issues. The authors discovered the importance of mental illness for both youth and young adults – for youth, mental health ranked 10th as reason for admission, was responsible for 2.8% of youth admissions, and had a mean length of stay of 5.4 days, while for young adults it

was ranked 4th, was responsible for 6.4% of adult admissions, and had the longest length of stay at 20.8 days (Young et al., 2011). Although there is an unfortunate lack of research on the topic, mental health should be an important clinical concern that is carefully monitored in adults with CP. Furthermore, specialized support and treatment plans are essential to care for patients who have a dual diagnosis of mental illness and CP (Lovell & Reiss, 1993).

The consequences of CP continue to evolve into and throughout adult life. It is unsurprising, therefore that some aspects of functioning decline with age and illness, as they would in the general population, and has been seen and reported particularly with respect to motor function. Adults with CP are recognized as frequently developing musculoskeletal problems including fatigue, pain and premature decline in mobility and function as they age (Rosenbaum & Rosenbloom, 2012). For some people with CP, functional decline begins in adolescence, and is seen particularly in those who are more severely affected by CP (e.g., GMFCS levels III, IV, and V) (Hanna et al., 2009). Cross-sectional studies, such as those of Murphy, Molnar, and Lankasky (1995) and Bottos, Feliciangeli, Sciuto, Gericke, and Vianello (2001), have noted that significant percentages (up to 40%) of adults with CP who could walk in adolescence lost the ability over the course of the next two decades. The causes of any decline require careful and individual assessment, as they are likely due to increased body size following growth spurts in adolescence, decreased physical activity, osteoporosis, increased muscle spasticity, hip and knee problems, pain and impaired balance (Rosenbaum & Rosenbloom, 2012). It is of great importance to acknowledge that at least some of these challenges are probably secondary conditions that may be preventable to some extent and could be reduced or eliminated by readily-available primary healthcare and health-promoting interventions.

CP can no longer be considered a disease of children. For the last 50 years the routine use of antibiotics has protected even those with the most severe forms of CP from the previously inevitable early death from pneumonia (Blair, 2010). Additionally, the introduction of gastrostomy tubes (i.e., tube feeding) in children with neurodevelopmental disabilities has been demonstrated to minimize the stress and frustration associated with feeding, and eliminate coughing, choking, vomiting and aspiration leading to pneumonia (Rempel, Colwell, & Nelson, 1988; P. Sullivan, 2009). Now half of children with even the most severe forms of CP will survive to adulthood, but because this longevity is relatively recent, there is no empirical experience of their life expectancy past middle age (Blair, 2010). The last two decades have seen significant developments in the medical management of people living with CP, with an increasing number of specialist services from a wide spectrum of disciplines becoming involved in the care of these individuals (Cooley & American Academy of Pediatrics Committee on Children With Disabilities, 2004). Because the role of care coordinator seems increasingly to be falling to the general practitioner or family medicine physician (Bodenheimer, 2007; Viner, 1999), a sound understanding of the concept of CP within general practice is becoming mandatory.

1.3. Primary Care of Patients with Cerebral Palsy

Throughout the 20th century, developmental paediatricians and orthopaedic surgeons managed the primary medical care of people with CP (Aisen et al., 2011). This approach continues to some degree today with diagnoses and testing being performed primarily by paediatric specialists. The treatment goals for CP traditionally placed emphasis on therapies to promote walking, realignment of joints, and increased comfort, while decisions about whether to do surgery and what surgical approach to use were based on evidence from clinical case reports

and the individual surgeon's judgment (Jones et al., 2007). The effects of changes in gait pattern as patients grew and the transition of patients from children into adults were generally not taken into account, and reasons for this are largely grounded in dominant social values regarding walking and disability (Gibson, Teachman, Wright, Fehlings, Young, McKeever, 2012). Many people with CP, however, now live well into adulthood. Patients in their 20s, 30s, and 40s frequently try to avoid changing specialists and continue to seek care from their treating paediatrician (Aisen et al., 2011; Oskoui, 2012), which leads to inappropriate use of healthcare services. Furthermore, because CP has traditionally been viewed as a disorder of childhood, adult specialists in primary care, internal medicine, and neurology receive little education regarding management of CP in residency training programs (Binks, Barden, Burke & Young, 2007; Patel & O'Hare, 2010).

The operational definition of primary healthcare varies largely throughout the literature (Haggerty, Burge, Levesque, Gass, Pineault, Beaulieu & Santor, 2007); however, as a conceptual model primary healthcare encompasses primary care, disease prevention, health promotion, population health, and community development within a holistic framework with the objective of providing essential community-focused healthcare (Schultz & Hatcher, 1997; World Health Organization, 1978). The Institute of Medicine (IOM) (1994) describes primary healthcare as, “the provision of integrated, accessible healthcare services by clinicians who are accountable for addressing a large majority of personal healthcare needs, developing a sustained partnership with patients, and practicing in the context of family and community” (p.1). This definition also recognizes the greater complexity of health care delivery in an era of rapid and profound changes – marked by the development of increasingly integrated healthcare systems – and the greater interdependence of healthcare professionals in the provision of health services (Hogg, Rowan,

Russell, Geneau, & Muldoon, 2008). The only service rendered by paediatricians that is not considered primary health care is specialist consultation. Otherwise paediatricians often provide primary healthcare services to individuals with complex childhood-onset disorders.

Adults with CP require ongoing health services to continue to monitor for needs that were present in childhood. Feeding difficulties, GERD, constipation, seizures, progressive scoliosis, contractures and dislocations secondary to chronic spasticity continue to be important medical issues to address (Oskoui, 2012). Access to routine care, dental care and screening are also important, such as cardiovascular health, pap smears, and mammography tests. There are, however, a number of new health issues that emerge in adulthood for this patient population. Overuse syndromes, chronic pain and fatigue, osteoarthritis and osteoporosis, and overall decline in mobility have all been reported among adults with CP (Haak, Lenski, Hidecker, Li, & Paneth, 2009).

Access to rehabilitation therapy and even to primary medical care for patients with CP can become difficult after 18 years of age, possibly because CP continues to be seen by the clinical community as a paediatric disability (Aisen et al., 2011). Children and adults with CP need comprehensive, coordinated care focused on preventing complications (e.g., malnutrition, skin breakdown, pain) and promoting improved self-management skills, which could ultimately improve health, quality of life, and access to education and vocational opportunities. Ideally, care should be provided by a consistent team that can assess and treat the primary and secondary effects of CP and common comorbidities, as well as provide primary and specialty medical care, rehabilitation, psychosocial treatment, and support for the patient and family (Aisen et al., 2011).

For children with CP, family-centered care is an accepted component in achieving maximum independence, especially for patients with cognitive impairment. The United States

Maternal and Child Health Bureau (MCHB) declares that the objective of family-centered care is to ensure that families of children with special health care needs will have the opportunity to partner in decision making at all levels, and promote satisfaction with the services they receive (National Center for Cultural Competence, 2007; US Department of Health and Human Services, Health Resources and Service Administration, & Maternal and Child Health Bureau, 2004). The family-centered care approach respects a family's uniqueness, transcends cultural boundaries, and recognizes that the family unit is the most important and constant context for an individual with disability (Cooley & American Academy of Pediatrics Committee on Children With Disabilities, 2004; Jeglinsky, Autti-Ramo, & Brogren Carlberg, 2012). Family-centered care can facilitate a smooth transition by ensuring that the role of family in the transition process is promoted. For many adolescents transitioning to the adult healthcare system, especially for young adults with the most significant and disabling conditions, the role of family changes, but remains vital (Scal, 2002). However, it remains true that while family-centered care is an important consideration throughout the transition process as described by the Shared Management Model in shifting the responsibility of care onto the young adult with CP, too much emphasis on family-centered care can result in the young adult losing a level of autonomy. In a study describing the negotiation of autonomy between young adults with mild intellectual disabilities and their family members, the authors noted that the concept of autonomy within the family cannot be approached or considered in isolation, rather it appears to be a product of a number of interdependent and intricately associated influences (Mill, Mayes & McConnell, 2010).

1.3.1. Additional Barriers and Challenges

Fragmentation of care may interfere with comprehensive primary healthcare. Many children with chronic conditions or disabilities receive the majority of their medical care from medical specialists (e.g., paediatricians) or sub-specialists (e.g., paediatric orthopaedists) or in specialty clinics that do not provide routine health care management (Allen, Vessey, & Shapiro, 2010). When young adults with CP are shuffled from specialist to specialist, they often miss the routine health screenings, developmental assessments, anticipatory guidance, and immunizations that their healthy age-mates receive (Allen et al., 2010). The development of medical specialization has improved the life expectancy of children with special healthcare needs, but has also resulted in fragmentation of health care delivery and increased medical costs (Bodenheimer, 2007). In a study that examined patterns of health care utilization among youth and young adults with CP, Young et al. (2011) found that the most predominant clinical issues leading to hospital admission for both youth and young adults with CP were epilepsy and pneumonia. Epilepsy and pneumonia are positively affected by appropriate access to primary care, by which regular preventative care and surveillance of secondary conditions occurs. The study also found that adults with CP had longer lengths of stay in hospital (9.6 days) as compared to youth with CP (6.4 days). Longer than expected hospital admissions are costly (Murphy, Hoff, Jorgensen, Norlin, & Young, 2006) and patients are negatively impacted the longer they are admitted.

Primary care providers frequently cite lack of specialty knowledge, inadequate time with patients and their families, inadequate reimbursement for care of children with complex medical or behavioural conditions, and unavailability of specialists to collaborate within their community as barriers to their provision of comprehensive care to young adults with chronic conditions (Binks et al., 2007; Okumura et al., 2010). Researchers believe that many of the barriers

identified by primary care providers in providing quality care to young adults with childhood-onset chronic diseases are amendable to changes in practice-level improvements, such as implementation of a medical home model (Okumura et al., 2010).

1.4. Healthcare Transition

Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. Paediatric healthcare services in Ontario expire when the patient reaches 18 years and all healthcare management is to be obtained from medical providers in the adult healthcare system. The goal of a planned health care transition is to maximize lifelong functioning and well-being for all young adults, including those who have special health care needs. The Canadian Paediatric Society (2007) defines healthcare transition as “a purposeful, planned movement of adolescents with chronic medical conditions from child-centered to adult-oriented health care” (p.786). This process includes ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the young person moves from adolescence to adulthood (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Transitions Clinical Report Authoring Group, 2011). A well-timed transition from child- to adult- oriented health care is specific to each person and ideally occurs between the ages of 18 and 21 years following the expiration of paediatric services (Blum et al., 1993). Although, with the knowledge that paediatric services expire at 18 years of age, healthcare transition should begin much earlier in preparation for a decrease in services. Coordination of patient, family, and provider responsibilities enables young adults to optimize their ability to assume adult roles and activities.

With reasonable biological certainty, most adolescents transition to adulthood. There is less confidence in the appropriate time for transition of young adults with chronic disabilities of

varying severities. There is even less certainty of the manner in which health care professionals should support this transition. Transition planning, when present at all, can be inexplicit, incomplete, or late. The transfer of care to an adult medical home and to adult medical specialists has also been described as more of a drift away from paediatric care rather than a clearly planned and executed handoff (American Academy of Pediatrics et al., 2011; Blum et al., 1993; Canadian Paediatric Society, 2007).

Healthcare transition research has primarily been directed at the development of position papers (Blum et al., 1993), consensus statements and guidelines for the care of adults with developmental and physical disabilities (American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine, 2002; Canadian Paediatric Society, 2007; Sullivan et al., 2011). The objective is to improve healthcare transition processes, and the effective implementation of both general and condition-specific transition programs (Grant & Pan, 2011). However, most paediatric practices (not including tertiary paediatric hospitals) do not routinely offer transition support services. Only one third of paediatricians report making referrals to adult physicians for even some of their patients, and less than 15% provide transition educational materials to adolescents and their parents (McManus, Fox, O'Connor, Chapman, & MacKinnon, 2008). Research reveals that paediatricians remain poorly informed about the conclusions of published consensus statements and that most primary care paediatric practices neither initiate transition planning in early adolescence nor offer transition-support services (Burke, Spoerri, Price, Cardosi, & Flanagan, 2008). This means that for many adolescents a smooth transition to the adult healthcare system may not be a reality.

As documented in the growing healthcare transition literature, multiple provider, patient/family, and system-level issues contribute to the slow progress of implementing an ideal transition process (Gorter, Stewart, & Woodbury-Smith, 2011). These issues range from the limited time available to prepare adolescents and their families, to resistance by young adults and families to leave paediatric care, and the reluctance of providers to discharge patients and families with whom they have a long-term connection and who do not have the requisite knowledge and skills to successfully negotiate the adult system (Binks et al., 2007; Reiss et al., 2005). Studies have reported a lack of availability of needed treatment services in the adult health care system (Reiss & Gibson, 2002), ranging from adult specialists to specific interventions. Treatment services, when available, are often not viewed as comparable to paediatric care. Providers, families, and young adults reported that some important life-sustaining treatments are only available in a paediatric treatment setting and indicated that on the basis of their personal experiences, the medical knowledge and experience necessary to manage childhood-onset chronic diseases is often not evident from adult care providers or facilities (Rosen, 1995).

Across Canada, transition programs have been designed and implemented in various tertiary paediatric facilities and healthcare organizations with the intention of providing a smooth transition from paediatric to adult healthcare. Grant and Pan (2011) compared and contrasted five well-known transition programs in Canadian paediatric facilities for chronically ill adolescents against the Canadian Paediatric Society (CPS) and the Society of Adolescent Health and Medicine (SAHM) recommendations for best practice or “Transition Principles”. The five programs reviewed were the “ON TRAC” model of transition care (Paone, 2001) at the Children’s and Women’s Health Centre of British Columbia in Vancouver, the “Good2Go”

Shared Management Model located at the Hospital for Sick Children in Toronto (Good2Go Transition Program, 2009), the “Maestro Project System Navigator” Model (Van Wallegghem, 2006) launched in 2002 by the Winnipeg Regional Health Authority for young adults with diabetes, the “Be Your Own Boss (BYOB)” program (Alberta Health Services, 2008) offered to transitioning young adults in Edmonton, and finally, the “Young Adults with Rheumatic Diseases (YARD)” clinic located at the Calgary Foothills Hospital (Guelber, 2008).

After detailed comparison of the programs, the authors found that only the ON TRAC Model and Good2Go Shared Management Model met all of the transition principles recommended by the CPS and SAHM (Grant & Pan, 2011). The CPS and SAHM Transition Principles suggest that transition programs provide developmentally appropriate care, enhance patient autonomy, ensure collaboration between healthcare providers, teach skills of negotiation, apply graduation of responsibility to the adolescent, provide community resources, designate a professional who takes responsibility for the transition, provide the patient with a portable summary of their healthcare needs, and have current transition plans documented (Grant & Pan, 2011). However, while the ON TRAC and Good2Go transition programs seem to exceed the level of standard care in terms of transitional services, it is unknown whether a formal evaluation of their effectiveness has been completed for young adults who have transitioned through the program.

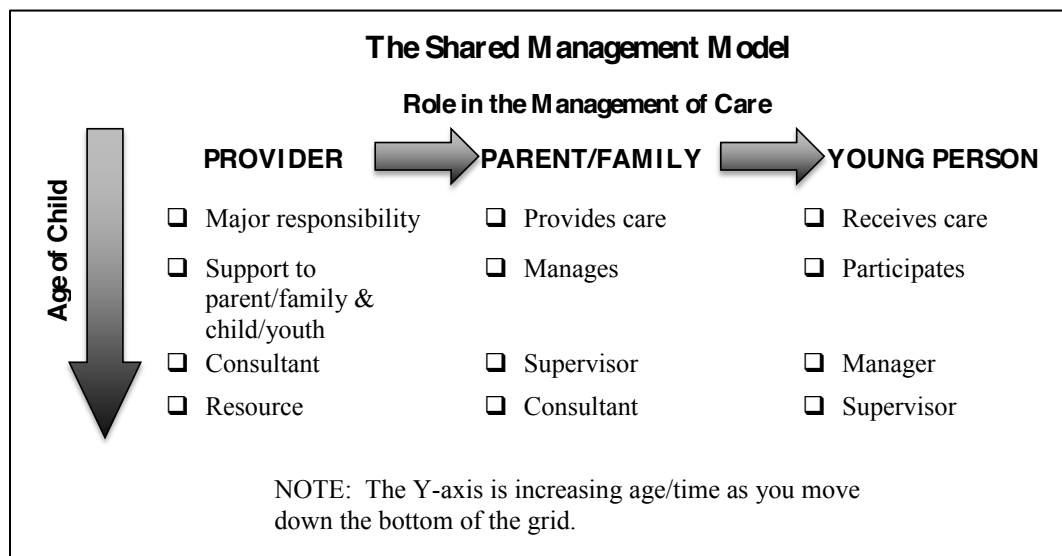
The many issues that can impede transition to adult health care for young people with chronic conditions are complex, and often idiosyncratic to communities, networks, or to individual providers (Rosen, 1995). What may be considered obstacles to transition that cannot be overcome in one setting may be entirely absent in another, and barriers that seem insurmountable may become negligible over time. Limited adoption of official transition processes between primary practice paediatric and adult care providers may also be the result of

physicians seeing transition as a new, distinct task that is being added to the many clinical activities that must be carried out during time-limited medical visits with adolescents (Cooley & Sagerman, 2011). This perception that healthcare transition is a new and separate service may be, in part, an unintended consequence of efforts to draw attention to the issue and change physician behaviours through the publicizing of numerous guidelines, consensus statements, and clinical reports (Cooley & American Academy of Pediatrics Committee on Children With Disabilities, 2004). However, whereas some transition-related tasks are fairly straightforward, such as developing a written transition plan or identifying adult care providers, most clinical activities that promote readiness for the eventual move out of paediatrics are integral to providing developmentally appropriate care. Such clinical activities include promoting a patient's self-management knowledge and skills (Kennedy, Sloman, Douglass, & Sawyer, 2007; Kieckhefer & Trahms, 2000), and meeting with adolescent patients individually for part of the medical visit (Stewart, 2009).

1.4.1. Shared Management Model

The Shared Management Model (see Figure 1) was designed based on the principles of *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*, developed in response to the need for a new healthcare supervision model merging preventive and health promotion needs of infants, children, and adolescents in the United States (Kieckhefer & Trahms, 2000). The Bright Futures Model begins with the development of a therapeutic alliance with the family and health practitioner when the child is an infant and progresses through a continuum of social, developmental, and health outcome achievements that help shape an independent, healthy adult (Green, 1994). Kieckhefer and Trahms (2000) believed children with chronic conditions should achieve these same health outcomes in a similar step-wise

manner, and therefore designed the Shared Management Model to enable young adults to be shared managers of their chronic health conditions. The model describes the development of an early therapeutic alliance between the children/youth², families and health-care providers as being essential to allowing young people with chronic conditions to develop into independent, healthy, functioning adults (Kieckhefer & Trahms, 2000). There is a strong emphasis on a gradual shift in responsibility where the leadership for care is shifted from the health professional to the parent, then ultimately to the youth (Gall, Kingsnorth, & Healy, 2006; Kieckhefer & Trahms, 2000). As the child ages, they actively participate in their health care in an age-appropriate manner. The health-care team and parent eventually move into consultant roles and the young adult, with new skills in self-management, eventually becomes the supervisor of their condition and healthcare needs (Gall et al., 2006).



Source: (Kieckhefer & Trahms, 2000)

Figure 1. The Shared Management Model

² The term youth is used here to describe a person slightly younger than a young adult (17-21), but not a child. Youth would be in the 14-16 year age range.

Many transition programs and paediatric healthcare facilities in Canada have adopted the shared management approach as the framework for their transition models, most notably the Good2Go Transition Program at the Hospital for Sick Children in Toronto (Good2Go Transition Program, 2009). The Shared Management Model has also become an international transition planning standard (The Royal College of Physicians of Edinburgh Steering Group, 2008). The Disability Services Commission in Western Australia has developed government policy describing the shared management approach and financial incentives for organizations to adopt the model for transitioning of youth with chronic conditions (Disability Services Commission, 2012). The guidelines used in Western Australia have expanded the traditional description of shared management by emphasizing the support required to allow adults with chronic disabilities to secure control over their needs and services, including financial responsibilities (Disability Services Commission, 2012).

The Shared Management Model emphasizes the importance of collaborative relationships between the young person, their family, and health-care providers with the intention of establishing an element of ‘independence’. The term ‘independence’ is used loosely due to the fact that, depending on the severity level of the condition, some young people may never reach true independence in the sense of having the ability to perform their own care, but should obtain autonomy to direct their own care. However, the concept of shared management still rings true regardless of severity, as the model moves to empower the family and/or caregivers to play a larger role in care management. Over time as the young person grows and develops, the model expects that the roles of the healthcare management team will change. This approach allows for a gradual shift in responsibilities and expectations related to leadership for health care and life decisions, as the youth is developmentally ready to take on new roles. The Shared Management

Model is an ideal framework for transition planning as the move from paediatric to adult health care includes preparing the young person to take developmentally appropriate responsibility for his/her health and health care (Cooley & Sagerman, 2011).

It should be noted that the Shared Management Model was developed for use initially at the Seattle Children's Hospital in Seattle, Washington (2000), and is most notably used in Canada at the Hospital for Sick Children (2009) and Holland-Bloorview Kid's Rehabilitation Hospital (2009) in Toronto; all large tertiary centres specializing in providing health services for children with special health needs. The Shared Management Model offers a simple framework to shift healthcare management from the provider to the young adult. However, the model is limited in explaining the shared care between paediatric and adult healthcare providers throughout the transition process. Communication between paediatric and adult providers is a well-cited barrier to effective health care transition of young adults (Binks et al., 2007). In smaller communities without the supports and resources that are available at larger tertiary centres, inclusion of communication and shared care between providers as part of the Shared Management Model is even more crucial. Paediatricians and adult providers must work together with a shared care approach, as well as with the parents and youth. Understanding the role that parents play in transition starts with recognizing that they may have critical information that their children may not provide, and by taking the shared management, family-centered approach, the primary care of individuals with chronic conditions becomes less overwhelming for the provider (Gorter et al., 2011; Peter, Forke, Ginsburg, & Schwarz, 2009).

1.5. Changing Face of Family Medicine in Ontario: Providing a Medical Home

In 1969, Canada adopted a universal health insurance program funded jointly by the provinces and the federal government with each province assuming responsibility for its own

health care system according to national guidelines (Fierlbeck, 2011). During its initial years, Ontario's health care system appeared well funded and worked to the satisfaction of most Ontarians (Fierlbeck, 2011). However, by the mid-1980s family physicians (the only primary care physician specialty in Canada) began to struggle to meet demands of their practices, and physician shortages began to appear (Pong, 2008). Most physicians were in solo or small-group fee-for-service practices and felt pressured to provide more visits (a cost-saving approach) in the face of healthcare costs rising (Rosser, Colwill, Kasperski, & Wilson, 2010). Physicians voiced concerns about the quality of the primary care that could be delivered and about the impact of the pressures on their personal lives (Rosser, Colwill, Kasperski, & Wilson, 2011). Some narrowed the scope of their practices and others increased referrals to specialists, feeling too overloaded to care for the more complex patients (Rosser et al., 2011).

In 1999, the Ontario College of Family Physicians published a policy document outlining directions for family medicine, and *Healthcare Papers* featured the College's vision of a patient-centered medical home (Rosser & Kaperski, 1999). It was the 2004 provincial elections that brought a new political party to power with the promise that every resident would have a family doctor. This new provincial government introduced Family Health Teams (FHTs) to Ontario's health care landscape (Ministry of Health and Long-Term Care, 2012a). FHTs evolved from several earlier Ontario pilots, among which are Community Health Centers (CHCs), Family Health Networks (FHNs), and Family Health Groups (FHGs) (Muldoon, Rowan, Geneau, Hogg, & Coulson, 2006). CHCs which originated in 1980, are more likely to serve rural, low-income, or minority populations; physicians are reimbursed by salary, and practices are likely to have multidisciplinary teams with emphasis on nursing support (Muldoon et al., 2006). FHNs, initiated in 2001, serve general populations, and reimburse physicians on a blended funding

formula based on capitation with additional financial incentives (Muldoon et al., 2006). Shortly after, FHGs formed, which are essentially the same as FHNs, except physicians are reimbursed on a fee-for-service basis with bonuses (Muldoon et al., 2006). The new FHT model includes multidisciplinary clinicians including an emphasis on the use of nurse practitioner clinics to assist the family physician and expand the overall scope of the practice (Rosser & Kaperski, 1999). Well over half of Ontario's population is now registered in one of these models, whereas most primary care for other provinces continues in independent fee-for-service practices (Ministry of Health and Long-Term Care, 2012a). The continued task of registering Ontarians with a primary care practitioner in one of the above team-centered models is essential in reaching the provincial goal of providing all residents with a medical home.

In the medical home, responsibility for care and care coordination resides with the patient's personal family physician working with a health care team. Teams form and reform according to patient needs and include specialists, midlevel providers, registered nurses, nurse practitioners, social workers, care managers, dietitians, pharmacists, physical and occupational therapists, family, and community members (Rosser et al., 2010). Medical home models vary but their success depends on their ability to focus on the needs of a patient or family one case at a time, recruiting social services, specialty medical services, and patient capabilities to solve problems (Rosenthal, 2008). Ontario's FHT model, implemented in 2005, may be North America's largest example of a patient-centered medical home (Ministry of Health and Long-Term Care, 2012a). The model, based on multidisciplinary teams and an innovative incentive-based funding system, has been developed primarily from fee-for-service primary care practices, and more than 2 million Ontarians are now served by over 200 FHTs across the province (Ministry of Health and Long-Term Care, 2012a).

1.5.1. Section of Family Physicians with Special Interests or Focused Practice

The adoption of FHTs and the intense focus of the medical home model have improved access to primary healthcare in Ontario (Rosser et al., 2011); however, the proportion of general practitioners or family physicians is not increasing as much as the proportion of specialists in Canada (Organization for Economic Co-operation and Development, 2007). Due to factors such as career choices and reduced working hours, many countries are experiencing a relative shortage of primary care physicians, particularly in Canada, Australia and the United States (Simoens & Hurst, 2006). A growing proportion of general practitioners are restricting their practice, which diminishes access to primary care providers particularly in rural and remote regions (Beaulieu, Rioux, Rocher, Samson, & Boucher, 2008). For example, in Canada 20% of family physicians polled in the 2007 National Physician Survey planned to limit their scope of practice in the coming year (College of Family Physicians of Canada, Canadian Medical Association, & Royal College of Physicians and Surgeons of Canada, 2007).

Some argue family physicians' traditional large scope of practice is unrealistic in an era when knowledge is growing exponentially (Beaulieu et al., 2008). One response to this challenge, the development of the 'specialized family physician', seems particularly attractive not only to a new generation of family physicians, but also to some health care managers and administrators (Green & Fryer, 2002; Rosser, 2002). In a study interviewing 92 family medicine residents and medical educators from all 17 medical schools across Canada, participants described the overwhelming nature of studying to be a family physician and some concluded that it felt impossible to sustain a wide scope of practice. Even those who were comfortable with a non-specialist/non-expert status acknowledged the importance of "being an expert in something"

(Beaulieu et al., 2008, p. 1158), which led to their decision to specialize or focus their future practices.

The trend in moving away from broad-spectrum, generalist primary care into specialized roles is a challenge for the discipline of family medicine. It has challenged the very definition of ‘family doctor’ by generating groups of family physicians whose practice interests are no longer seen to be at the core of family medicine and because the number of physicians in any particular special-interest practice is small, family physicians often struggle to network with each other and find support (Bailey, 2007). Family physicians who commit increasingly more practice time to areas of special interest could potentially add to the strain of physician shortages in Canada, as it is a challenge to find enough comprehensive primary care physicians to replace those who move into focused practice. On the other hand, recognizing the seeming inevitability of family physicians focusing their practices represents an opportunity to capture their skills in a way that will benefit family medicine (Gutkin, 2008). In 2008, the College of Family Physicians of Canada’s (CFPC) Board of Directors approved the report and recommendations of its Steering Committee on Family Physicians with Special Interests and Focused Practices (SIFP) (College of Family Physicians of Canada, 2008). The SIFP includes a number of programs with each focusing on a particular type of care, such as addiction medicine, mental health, and developmental disabilities. Each program has a committee with mandates that include fostering continuing professional development and facilitating communication between physicians with the same interests (College of Family Physicians of Canada, 2008). While the trend of family physicians focusing their practice into an area of special interest could result in diminished access to important generalist physicians, others suggest that the movement may increase the number of services available to patients, particularly in team-based practices (i.e., family health

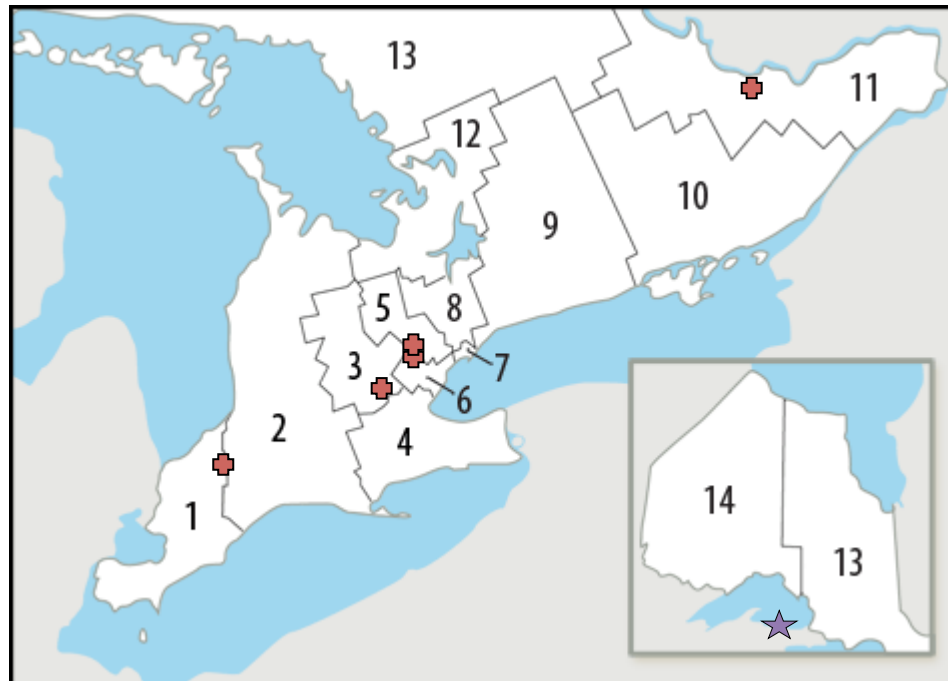
teams), and reduce wait times for some procedures or treatments typically performed only by specialists (Collier, 2011). At present there is no data to measure the impacts of SIFP on access to care.

1.6. Context of Primary Care in Sault Ste. Marie

Sault Ste. Marie, Ontario was chosen as the site of this research due to a combination of geographic and population based factors. Sault Ste. Marie is geographically isolated from the large tertiary hospitals in Ontario, with Toronto being the closest large centre offering specialty medical services at a distance of almost 700 kilometers (i.e., a 7 to 8 hour drive). Sault Ste. Marie, located in the Northeast Local Health Integration Network (LHIN), is the heart of the Algoma District with a catchment of approximately 115,000 people (74,000 within the city limits) spanning across 48,810 square kilometers of land (Statistics Canada, 2011). In 2011, the percentage of the population aged 65 and over in Sault Ste. Marie was 19.3%, compared with a national percentage of 14.8% (Statistics Canada, 2011). The percentage of the working age population (15 to 64) was 66.3% and the percentage of children aged 0 to 14 was 14.4%. In comparison, the national percentages were 68.5% for the population aged 15 to 64 and 16.7% for the population aged 0 to 14 (Statistics Canada, 2011). Although geographically isolated from large urban centres, the population size of Sault Ste. Marie warrants a large enough sample of persons living with CP (estimate based on prevalence rate in the literature) to ensure a general knowledge of the condition in the medical community and experience in caring for individuals with CP.

Sault Ste. Marie, Ontario also provides an excellent example of the changing structure and organization of primary health care in Ontario that was discussed in the previous section.

The typical practice of physicians in northern areas of Ontario is not the same as those in urban regions due to the medical certification (i.e., specialist vs. generalist) and geographic distributions across the province (Wenghofer, Timony, & Pong, 2011). A well-defined boundary separating northern from southern Ontario can be indicated using the Forward Sortation Areas (FSA) of Canadian postal codes, such that all FSAs beginning with 'P' are considered northern while all remaining FSAs represent southern Ontario (Wenghofer et al., 2011). The Ontario LHINs (see Figure 2) also provide regional boundaries between northern and southern Ontario, in that health services provided in northern Ontario are under the regional authority of the Northeast LHIN (#13) and Northwest LHIN (#14). Of the greater than 20,000 Ontario physicians, only 6% practice in northern regions of the province and 62.2% of these physicians are certified family medicine practitioners (Wenghofer et al., 2011).



- | | |
|-------------------------------------|--------------------------|
| 1. Erie St. Clair | 8. Central |
| 2. South West | 9. Central East |
| 3. Waterloo Wellington | 10. South East |
| 4. Hamilton Niagara Haldimand Brant | 11. Champlain |
| 5. Central West | 12. North Simcoe Muskoka |
| 6. Mississauga Halton | 13. North East |
| 7. Toronto Central | 14. North West |

Sault Ste. Marie, Ontario ★

Children's Hospitals ⛶

Source: (see <http://www.lhins.on.ca>)

Figure 2. The Local Health Integration Networks (LHINs) of Ontario

Specialist physicians are few and far between in northern Ontario, which can be problematic for people with complex medical disorders, such as CP. For example, although it is an urban northern community, Sault Ste. Marie has only five practicing paediatricians, but close to 100 family physicians serving the city (College of Physicians and Surgeons of Ontario, 2013).

From this data, there is reason to believe that there are family physicians in northern Ontario cities who will ultimately have a wider scope of practice that includes persons with complex paediatric-onset disabilities.

Sault Ste. Marie, and much of Ontario supplement a lower volume of physicians by utilizing locum services and the Ontario Telehealth Network. A locum refers to a physician who travels to a community from their home practice location and assumes another physician's clinical duties on a temporary basis (Health Force Ontario, 2013). Locums are a valuable component of the physician workforce because they enable relief for community physicians, and also fill the gaps in communities where specialist services are limited or non-existent (Health Force Ontario, 2013). Patients requiring specialized medical services not available in their community may also need to travel to larger centres in Ontario to access care. The Ontario Telehealth Network (OTN) aids in limiting the amount of travel required by providing videoconferencing between patients in their hometown and their out-of-town physicians (see <http://otn.ca> for more information). Locum physicians may set up regular clinics in Sault Ste. Marie or return on a random schedule for a few days or few weeks at a time.

Sault Ste. Marie has a multifaceted healthcare system that includes support personnel, equipment, diagnostics, support groups, as well as both acute and long-term health organizations. The new Sault Area Hospital opened its 289-bed facility in March 2011 and serves the entire Algoma District with enhanced core programs including critical care, oncology and radiation, emergency services, surgical, and rehabilitation (SaultMed, 2012). Primary healthcare in Sault Ste. Marie is mostly accessed through the Algoma District Medical Group (ADGM) located at the Group Health Centre. Primary healthcare services are also available through independent care providers, and the newly developed Superior Family Health Team (SFHT) and Baawaating

Family Health Team (BFHT). The Sault Area Hospital also has a department of family medicine, through which some primary healthcare services are accessed. See Table 1 for the distribution of Sault Ste. Marie family physicians and paediatricians by practice location.

Table 1. Distribution of Sault Ste. Marie Family Physicians and Paediatricians by Primary Practice Location

Specialty	ADMG	Hospital	Independent	Locum	Nursing Home	SFHT	BFHT	Total
Family Medicine	40	31	14	2	1	8	1	97
Paediatrics	4	0	1	0	0	0	0	5
Total	44	31	15	2	1	8	1	102

Source: (College of Physicians and Surgeons of Ontario, 2013)

1.6.1. The Algoma District Medical Group/Group Health Centre

The Group Health Centre in Sault Ste. Marie is Ontario's largest and longest-established, membership-based health organization and is home to more than 60 physicians across multiple specialties with a support staff of over 300 (e.g., nurses, social workers, therapists, technicians, clerical) (SaultMed, 2012). The Group Health Centre is a partnership between the ADMG, an independent medical group, and the Group Health Association (GHA), an independent, not-for-profit corporation. The partnership represents an innovative approach to providing community-based health care. Representatives from the ADMG are members of the Group Health Centre Joint Management Committee, which proposes policy to the Board of Directors and Medical Corporation (Health Council of Canada, 2009). The GHA, which owns the physical facilities, is responsible for hiring all non-physician personnel (Health Council of Canada, 2009).

The Group Health Centre was built on the principles of group medical practice, consumer sponsorship, and the prepayment of medical insurance (Group Health Centre, 2013b). The Group Health Centre's core philosophy is to provide patient-centered care, emphasizing patient education and self-management (Group Health Centre, 2013b). Currently, the Group Health

Centre's more than 60 physicians and associates and over 300 allied health professionals provide services to a registered population of more than 57,000 patients (Health Council of Canada, 2009). The ADMG is home to 40 of Sault Ste. Marie's 97 family physicians and four of the city's five practicing paediatricians (See Table 1) (College of Physicians and Surgeons of Ontario, 2013; Group Health Centre, 2013a).

1.6.2. Superior Family Health Team & Baawaating Family Health Team

In 2009, a few of Sault Ste. Marie's independent family physicians collaborated to open the Superior Family Health Team and SaultCare walk-in clinic (Superior Family Health Team, 2012). The SFHT is home to eight family physicians and builds multi-disciplinary teams unique to patient needs by utilizing the various specialties throughout the city (Superior Family Health Team, 2012).

The Baawating Family Health Team (BFHT), which opened in 2011, is a community sponsored FHT operating out of the Batchewana First Nations Health Centre with a focus on the First Nations community in and around Sault Ste. Marie (Baawaating Family Health Team, 2013). The BFHT has a staff of six including a single lead family physician, nurse practitioner, registered practical nurse, and social worker (Baawaating Family Health Team, 2013).

1.7. Systems Thinking and Complexity Theory as a Foundation for a Study on Healthcare Transition

Healthcare organization is a complex adaptive system, and can be defined as a set of connected or interdependent parts or agents – including caregivers and patients – bound by a common purpose and acting on their knowledge (Plesk, 2001). Systems thinking or complexity theory is the theoretical approach to understanding complex adaptive systems (Hamandi, Jetha, & Norman, 2011). Healthcare transition research has been criticized for being largely

descriptive and lacking a theoretical foundation (McDonagh & Kelly, 2010; Stewart, 2009). The mechanistic approach to understanding problems associated with healthcare transition does not account for the complex interactions of the multilevel influences on the transition process (Hamdani, Jetha, & Norman, 2011), such as the unique healthcare needs of each individual, the developmental readiness for self-management, and the extent and quality of external supports from both family members and health practitioners (Young, 2007). Discussions of healthcare transition processes have been shaped by a mechanistic model, suggesting that if the transition process were broken down into its parts that it could be fixed, such as by improving self- or shared-management by youth (Gall et al., 2006; Schultz & Liptak, 1998), or improving discharge and transfer procedures in paediatric services (Young, 2007). Although many of the recommendations that result from healthcare transition research are of a more mechanistic approach, the literature recognizes the complexity and challenges associated with transition, which provides evidence that new conversations have started that challenge contemporary frameworks in healthcare research (Martin & Sturmburg, 2009).

Healthcare transition from paediatric to adult healthcare services for young adults with childhood-onset disabilities is a complex and dynamic phenomenon and is continually influenced by multiple factors (Binks et al., 2007; Reiss & Gibson, 2002). These factors can be described at various levels of interaction. The skills and knowledge for self- or shared-management are influencing factors at the individual level (Gall et al., 2006), as well as family support at the interpersonal level (Reiss et al., 2005), training of healthcare providers, and co-ordination between paediatric and adult services at the organizational level (Young, 2007), and resources to support the transition to adulthood at the policy-making level (King, Baldwin, Currie, & Evans, 2006; Reiss & Gibson, 2002; Viner, 2008). It is important to view the challenge of supporting

successful transition to adult healthcare as a whole with interactions and relationships between factors and levels, attempts at fixing the gaps in the transition process will continue to fail resulting in unanticipated consequences and poor outcomes.

Systems thinking is an emerging perspective that may provide a beneficial approach to health systems research and practice. A notable Canadian example of an emerging and evolving discourse about complex systems in health services research and quality improvement is Glouberman and Zimmerman's (2002) report to the Romanow Commission in Canada. The report noted that most approaches used to apply change in our health care system are based on a rational planning approach. However, assumptions underlying rational planning are inconsistent with complex adaptive systems. Other examples of complex systems discussion in healthcare from the United States include the Institute of Medicine's report 'Crossing the Quality Chasm' (Plsek, 2001), as well as the successes of taking a systems approach to tobacco control on overall smoking rates within the Veterans Affairs health services clients (Sherman, 2008) and in the broader health systems, against major resistance by the licit and illicit tobacco industry (White & Bero, 2004). Although most of the experts and advisors have recognized that the health field and its problems are not simple, there is limited discussion of the theoretical frames of complex systems and how to intervene in such systems.

Built upon the foundations of complexity theory, systems thinking recognizes the phenomenon of healthcare transition as a complex adaptive system (Hamdani et al., 2011). A complex adaptive system is defined as "a collection of individual agents with freedom to act in ways that are not always totally predictable, and whose actions are interconnected so that one agent's actions changes the context of the other agents" (Plsek & Greenhalgh, 2001, p. 625). The high degree of interconnectedness between influencing factors means that a change in one

area of the system affects other areas. Such interactions can also produce consequences that are unpredictable and unintended (Wilson & Holt, 2001). For example, the advances in medicine and technology in the 1980s increased the lifespan of children with disabilities (Cooley & American Academy of Pediatrics Committee on Children With Disabilities, 2004; Stewart, Law, Rosenbaum, & Willms, 2001), which led to increased needs for health services into adult life beginning in the 1990s (Reiss & Gibson, 2002). However, an extended lifespan also meant that young people with disabilities were no longer eligible for paediatric services, and as a result they lacked appropriate health care and faced greater risks of secondary conditions and increased mortality (Reiss & Gibson, 2002). In this example, medical interventions led to direct increases in life expectancy, while also producing the unintended consequence of a lack of access to appropriate health services (Stewart, Stavness, King, Antle, & Law, 2006; Young, 2007). Therefore, by understanding healthcare transition as a complex system that evolves over time, we are better able to recognize the challenges healthcare providers are experiencing, and in terms of solutions we are provided with a clearer direction for formulating research questions that account for both intended and unintended consequences.

1.8. Chapter Summary

People with CP are living well into their adult lives due to advances in medical technology, research and education. Therefore, continued, comprehensive, and age-appropriate medical care is required to maintain the health of adults with CP as they age beginning with a timely, educational, and therapeutic transition from paediatric care to adult-oriented health care. Adults with CP have difficulty accessing appropriate services. Various studies have identified common barriers to transition of young adults with chronic childhood disabilities, such as paediatricians' inability to "let go" of their patients and the lack of knowledge and experience in the adult sector

in caring for people with CP (Binks et al., 2007). Multiple position papers have been published outlining the definitions and stepwise actions for transitioning young adults into adult care (American Academy of Pediatrics et al., 2011; American Academy of Pediatrics et al., 2002; Canadian Paediatric Society, 2007; Cooley & American Academy of Pediatrics Committee on Children With Disabilities, 2004; Cooley & Sagerman, 2011; Reiss, 2012; Reiss et al., 2005). However, the fact that such guidelines continue to be published indicates a systematic problem with the approaches used to ‘solve’ the problem of healthcare transition. People with CP often have complex, multi-system health problems that frequently require various medical specialist appointments and assessments (Jones et al., 2007). In northern Ontario, medical specialists are few and far between, which means that family physicians often have a much wider scope of practice than their southern Ontario neighbours (Wenghofer et al., 2011), which likely includes providing primary health care for adults with CP.

This study will attempt to discover innovative solutions to combat transition barrier by quantitatively identifying the medical specialty service use of the paediatric population (ages 0-16) and transitioning young adults (ages 17-21) with CP in Sault Ste. Marie, Ontario, and qualitatively exploring transition barriers experienced by primary health care providers in Sault Ste. Marie. Ultimately, this research is intended provide insight into processes to improve quality health care services for adults with CP.

1.9. Research Questions

This thesis has three main research questions.

1. What are the differences and similarities in the use of medical specialties by children/youth (0 to 16 years) and young adults (17 to 21 years) with CP who live in Sault Ste. Marie, Ontario?

2. What are the barriers to transitioning young adults with CP from the paediatric to adult health care system in northern Ontario?
3. What innovative solutions may be implemented to address the identified transition barriers?
 - a. Would Special Interest or Focused Practice (SIFP) groups in family medicine aid in supporting the health care needs of adults with CP living in northern Ontario?

Chapter 2: Research Design

2.1. Chapter Introduction

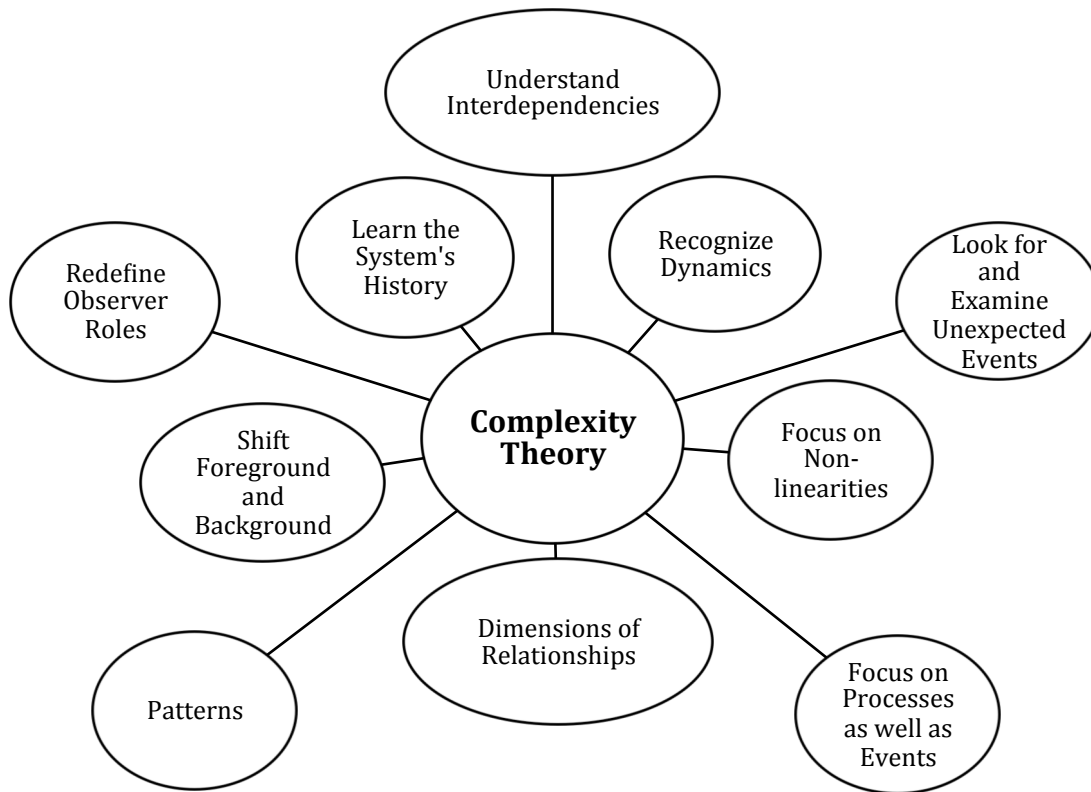
This mixed-methods case study used both quantitative and qualitative data to examine the primary health care transition of young adults with CP living in Sault Ste. Marie, Ontario, Canada. Sault Ste. Marie was selected as an instrumental case study to best understand the issues surrounding healthcare transition of young adults with CP. Sault Ste. Marie has a unique representation of various primary care organizations and medical specialist services, including the Group Health Centre (an especially unique form of combined primary care and specialist services) and two brand new FHTs. As a moderately-sized northern community, Sault Ste. Marie has a large enough population to ensure a valid representation of CP (sufficient prevalence); at approximately 3.3 per 1000 individuals (Arneson et al., 2009) and a catchment population of 115,000 people (Statistics Canada, 2011), the estimated prevalence of CP in Sault Ste. Marie and district is around 380 cases). However, there are relatively few medical specialists and virtually no paediatric sub-specialists (only five general paediatricians) practicing in Sault Ste. Marie (College of Physicians and Surgeons of Ontario, 2013). Therefore, the above characteristics mark Sault Ste. Marie as an ideal location for case study analysis of healthcare transition of youth and young adults with CP.

The Laurentian University Research Ethics Board granted ethics approval for this thesis on July 24th, 2012 (See Appendix A). The Joint Sault Area Hospital/Group Health Centre Research Ethics Board granted local ethics approval on November 26th, 2012 (See Appendix B).

2.2. Use of Case Study and Complexity Theory in the Research Design

The case study is a respected methodology described by Creswell (2012) as: “a type of design in qualitative research that may be an object of study, as well as a product of inquiry” (p. 97). Case study research is an approach in which the investigator explores a real-life, contemporary bounded system, through detailed, in-depth data collection involving multiple sources of information, and reports a case description as well as case themes (Creswell, 2012).

Researchers have often attempted to understand health care organizations and various health related processes by using case study designs; however, these designs are only as good as the theoretical model driving the research. In this thesis, complexity theory, or systems thinking, serves as a blueprint for framing a case study that explores a complex adaptive system (Anderson, Crabtree, Steele, & McDaniel, 2005), and is designed using complexity as the theoretical foundation for understanding the variable and complex nature of health care transition. A complexity perspective is especially prevalent in the analysis portion of the thesis design, in the sense that emerging themes from the physician interviews are coded from a complexity theory perspective. Anderson and colleagues (2005) have identified several potential extensions of case study design uniquely suited to carrying out a study designed from a blueprint of complexity theory (see Figure 3). These extensions include the importance of understanding interdependencies, as well as being sensitive to the relationships prevalent within the system are powerful tools used to increase the understanding of primary healthcare and healthcare transition for persons with CP in Sault Ste. Marie.



Source: (Anderson et al., 2005)

Figure 3. Extensions of Case Study Design Using a Complexity Science Blueprint

2.3. Quantitative Data: Claims History Database – Ontario Health Insurance Program (OHIP) Fee-for-Service Claims

The first research question was addressed using OHIP claims to examine the differences and similarities in the use of medical specialties by children and young adults with CP who live in Sault Ste. Marie, Ontario. The Claims History Database contains approved claim payments and service encounters from OHIP's medical claims processing system and captures approximately 180 million claims per year (Ministry of Health and Long-Term Care, 2012b). The database contains health services data submitted by providers (primarily physicians) from a variety of settings including independent health facilities, alternate payment programs, primary

care, academic health science centres, and hospitals, but does not include inpatient care (Ministry of Health and Long-Term Care, 2012b).

A formal data request was submitted to the MOHLTC on July 9th, 2012 for specific metrics (see Table 2) stored in the Claims History Database – Ontario Health Insurance Plan (OHIP) Fee-for-Service Claims between April 1, 2006 and March 31, 2012. The unit of analysis for the OHIP data is a single claim, which can be defined as a single episode of medical service use as described in the Schedule of Benefits for Physician Services under the Health Insurance Act (Ministry of Health and Long-Term Care, 2013). Since OHIP claims are made for individual services not individual patients, the list of claims generated for the request to the MOHLTC could include duplicates. To ensure this did not occur, the original request to the MOHLTC asked for duplicates to be removed (see Appendix C). In order to accomplish this, the MOHLTC data analyst first generated a list of patients that have had a diagnostic code for CP submitted to OHIP claims services. The analyst then removed all additional codes for each patient for that specific visit, resulting in a single list of unique patient claims. For example, if patient John Doe had a visit with his neurologist and in that visit, he had a standard physical assessment, which was coded to OHIP under the diagnosis of CP, but in the same visit also had billed claims for a neurological function exam, assessment of epilepsy medications, and Botox injections, then these last three claims were removed from the list generated by the MOHLTC data analyst. The request for the MOHLTC to remove duplicates prior to releasing the data also eliminated the need to request patient identifiers, resulting in line level (or claim level) data, not report level (or patient level) data.

Data could only be requested as far back as 2006 due to the fact that the MOHLTC changed their database collection guidelines, and 2006 is the first year data was made available

using the new system. Only claims submitted by physicians for patients who have had at least one diagnosis code for cerebral palsy (ICD-9 Diagnosis Code 343) were requested, as these claims provided a starting point for describing the medical specialist services used by children and young adults with CP.

Data was received and analyzed in Microsoft Excel format (.xls). Prior to analysis, the data was cleaned by limiting the data to include only patients between 0-21 years of age, and patients living in LHIN 13 (Northeast LHIN) with FSAs of P6A, P6B, P6C and P0S (Sault Ste. Marie forward sortation areas). Age of patient was subsequently split into two age groups labeled ‘Paediatric Age Group’ (0-16 years) and ‘Transition Age Group’ (17-21 years). After data cleaning, there were 14,813 unique claims (i.e., physician visits).

Table 2. Data Requested from MOHLTC OHIP Claims Database

Data Elements	Variables	Level of Measurement	Rationale
Patient	Sex	Nominal	For demographic differences in descriptive analysis (i.e. age categories, gender differences).
	Age in years	Ratio	
	LHIN	Nominal	
	FSA	Nominal	
Physician	Sex	Nominal	For demographic differences in descriptive analysis (i.e. age categories, gender differences).
	Age in years	Ratio	
	LHIN	Nominal	
	FSA	Nominal	
Service	Specialty Code	Nominal	To describe usage of medical specialty services (i.e. most frequent specialties used by each age group)
	Diagnosis Code	Nominal	

Data obtained from the Claims History Database underwent secondary data analysis with descriptive table visualizations of average age of the patient groups. Additionally, the representation of total claims submitted for each patient age group were calculated as a rate per 1000 individuals with CP using the 2011 Statistics Canada Census Profile for Algoma District and the estimated prevalence of CP as 3.3 per 1000 individuals (Arneson, et al., 2009). While the

calculated rate is an estimate, representing the number of claims per age group controls for the larger number of ages represented in the paediatric age group as compared to the transition age group. The estimate used in calculating this rate is known to be conservative in terms of the rate difference between the two age groups. A sensitivity analysis performed following completion of this study, which used a more accurate prevalence rate for the Northeast LHIN (2.2 per 1000 individuals), as well as changing the age groups to reflect the paediatric age group from 0-17 years and the transition age group from 18-21 years, resulted in an even wider discrepancy of medical claims between each age group (see Appendix D).

To answer Research Question #1 a pivot table identifying the number of claims submitted by physician specialty for each age group was created. Subsequently, the respective LHINs for the highest used physician specialties were analyzed to see which specialties were accessed from outside of Sault Ste. Marie. This frequency is important for discussion of locum services (i.e., physicians from out of town who travel to Sault Ste. Marie to provide service) and/or referrals to physicians out of town that patients travel to for care.

2.4. Qualitative Data: Physician Interviews

Interviews with family physicians and paediatricians in Sault Ste. Marie, Ontario were an important component for understanding their perspectives concerning the healthcare transition of young adults with CP including the barriers experienced (research question 2) and innovative solutions for addressing these barriers (research question 3).

The CPSO Doctor Search was used to gather the primary practice mailing addresses for family physicians and paediatricians in Sault Ste. Marie. A 'Dear Doctor' letter (see Appendix E) was mailed by the author to all 102 physicians as identified in Table 1 on August 20th, 2012. An 8-week 'Reminder' postcard (see Appendix F) was mailed on October 15th, 2012 to all physicians

for whom a response was not already received (either denying or accepting the invitation for an interview).

Of the 102 physicians contacted, 8 responded by email with 4 consenting to participate (Response Rate = 4%). The consenting participants included three family physicians (two from the ADMG, and one from the SFHT), as well as one paediatrician. Of the four physicians who responded by declining to participate, two indicated that their practice included only emergency medicine and they did not have a primary practice to comment on, and two indicated they did not have enough time available to participate. Physician non-participation in primary care research is a well-documented problem, with reservations towards participating evolving from time and workload issues (Salmon et al., 2007). A German study identifying barriers to participation in primary healthcare research found that some general practitioners (GPs) believed that research participation did not fall within the professional responsibility of GPs, while others perceived a lack of recognition or voice in the research process and some additionally feared being observed or measured by researchers (Hummers-Pradier et al., 2008). Although the physician response rate is very low, studies have suggested that non-participants and participant physicians are similar on most important characteristics, and validity of the study need not always be affected (Templeton, Deehan, Taylor, Drummond, & Strang, 1997).

Individual interview sessions were set up at the physicians' private offices, at which time the primary investigator reviewed the informed consent forms (see Appendix G). Following the informed consent process, interviews were conducted using a semi-structured interview script (see Appendix H). Interview questions focused on the typical care process for a person with CP from diagnosis into adulthood in Sault Ste. Marie, barriers to transition of young adults in Sault

Ste. Marie, and opinions of possible solutions to the transition gap and providing quality primary healthcare for young adults with CP in Sault Ste. Marie well into their adult lives.

Interviews were digitally audio recorded and later transcribed verbatim by the primary investigator and then exported to NVivo 10 Research Software (QSR International, 2012) for data management and analysis. Analysis of the case study began with a detailed description of the case in which certain aspects of the case emerge, such as a history of the case, chronology of events, or a day-by-day rendering of the activities of the case (Creswell, 2012). A detailed literature review on healthcare transition processes, cerebral palsy, complexity theory and a description of primary health care services in Sault Ste. Marie provided a foundation for the thematic analysis of this mixed-methods study. Thematic analysis of the interviews was conducted to facilitate understanding the complexity of healthcare transition for young adults with CP living in Sault Ste. Marie. Creswell (2012) notes that the thematic analysis must be rich in the context of the case, and in order to preserve the complexity associated with healthcare transition, themes were aligned with the case study extensions proposed by Anderson et al. (2005) as depicted in Figure 3. For example, as part of the data collection for this thesis, primary care physicians were asked to openly describe their practice and how they are involved in transition processes. One of the reasons for this open-ended question was to help identify diverse dimensions and elements that can impede the transition process.

Interview transcripts of the four participating physicians were coded following the use of an NVivo tool that provided a simple word frequency analysis to gain insight on the most popular topics discussed in the interviews (see Table 3 for a list of the top 10 topics). The thematic analysis of the interviews was at risk of biased coding due to the researcher having strong background knowledge of healthcare transition and healthcare organization in Sault Ste.

Marie. Therefore the NVivo word frequency tool was used to ensure rigor of the overall analysis. All transcripts were initially coded based on these frequent topics or subthemes and were informed by the literature to aid in selection of main themes for coding (see Table 4 for further details). A ‘cluster analysis’, another NVivo tool that provided Pearson correlation values, was used and allowed for related codes to be combined such that emergent themes could be developed.

Table 3. Top 10 Most Frequently Used Words

Frequently Used Word	Count
Family	53
Transition	25
Resources	22
Access	21
Work	21
Community	20
Support	17
Communication	14
Severe	12
Coordinator	11

Table 4. Example of Initial Coding Process of Physician Interview Transcripts

Interview Transcript	Initial Coding Framework
<p><i>Interviewer:</i> What are the benefits to how CP patients are cared for in the Sault? For example, what are the benefits of CP patients staying with the paediatricians?</p>	
<p><i>Paediatrician:</i> “Well there are benefits – that’s why we still have them [the patients]. The benefit is that we know them. We know that 5 years ago you tried valproic acid and it didn’t work. And we have all that history! We know the family well, and they often feel comfortable with you. You have the experience, and these kids are often very complicated. So that’s the real advantage. You have a fair group of patients like that, too, so you understand their issues and needs.”</p>	<p>Familiarity</p> <p>Family Expertise</p>
<p><i>Interviewer:</i> Do you think that’s the benefit for all cases, or maybe just more the severe cases?</p>	
<p><i>Paediatrician:</i> “Well, yeah, you’re right. It certainly would be for the more severe. And, if you think about the more mild to moderate cases, those generally are being transitioned. Like, I can’t think of any kids with really mild cerebral palsy that I look after who are 20. Even moderate, those adolescents are probably being cared for in the main stream. But, there isn’t really a process and it is probably just happening willy-nilly, you know? There hasn’t been any real communication or plan, I think in those cases, it just happens. Which may not be optimal.”</p>	<p>Severity of CP Transition</p> <p>Main Stream/Broad Spectrum/Adult Med Process Communication</p>

2.5. Chapter Summary

This thesis examined the types of medical specialty services accessed by children and young adults with CP in Sault Ste. Marie by examining OHIP billing claims with diagnostic codes of CP from the OHIP Claims Database. As well, this project explored transition processes, barriers and solutions for young adults with CP in Sault Ste. Marie by interviewing primary care providers (i.e. paediatricians and family physicians). These interview sessions not only provided examples of transition barriers, but also attempted to discover novel solutions to ensure that adults with CP in Sault Ste. Marie receive continued, age-appropriate and quality primary health care. The case study methodology used in this study allowed for preservation of the complexity associated with healthcare transition, and presents Sault Ste. Marie as an excellent case for extending our knowledge regarding healthcare transition for young adults with CP. The results that arose from this case study provide meaning to healthcare transition for young adults with CP as well as give insight to the future of primary healthcare services for this population.

Chapter 3: Findings

3.1. Chapter Introduction

The following chapter presents the results from the analysis of OHIP fee-for-service physician claims and the thematic analysis of interviews held with family physicians and paediatricians in Sault Ste. Marie, Ontario. While the extensive literature review included in this thesis offers an excellent background knowledge of the history of the healthcare transition system, analysis of the data collected for this study purposefully began with the quantitative OHIP claims data to answer the first research question: What are the differences and similarities in the use of medical specialties by children/youth (0 to 16 years) and young adults (17 to 21 years) with CP who live in Sault Ste. Marie, Ontario? Together the literature review and order of data analysis provided a base understanding of healthcare service utilization by youth and young adults with CP in Sault Ste. Marie, Ontario. The findings from the quantitative data then set the stage for interpretation of the thematic interview analysis from a perspective of complexity theory, and answered the second and third research questions: What are the barriers to transitioning young adults with CP from paediatric to the adult health care system in northern Ontario? And, What innovative solutions may be implemented to address the identified transition barriers?.

3.2. OHIP Claims History Data

The data received from the MOHLTC with data elements from the OHIP Claims History Database included a total of 14,814 claims for physician services³ rendered for patients from 0 to 21 years of age and diagnosed with CP in Sault Ste. Marie between the period of April 2006 and

³ Physician services include only consultations and medical assessments (i.e. physician visits)

March 2012. Prior to analysis, the data set was cleaned to include only those patients with a FSA of P0S, P6A, P6B, or P6C, to ensure that only patients with CP from Sault Ste. Marie were included.

3.2.1. Descriptive Statistics: Person Dimension

The two groups of people represented within the OHIP Claims dataset included the patients (service users) and the physicians (service providers). To align with the purpose of this study, the patient group was sorted and divided into two different age groups; the paediatric age group, which includes claims for patients between 0 and 16 years of age and the physicians who provided this care, and the transition age group, which includes claims for patients between 17 and 21 years of age and the physicians who provided this care. The purpose of dividing the patients into these two age groups was to demonstrate the changes in service utilization once specialty paediatric healthcare services expire. While individuals who are 17 years of age are still eligible to receive paediatric services, it is important to note that they are not eligible for new referrals to paediatric specialists/sub-specialists (Ministry of Health and Long-Term Care, 2013) and should be in the process of transitioning from their paediatric care providers to physicians in the adult healthcare system, which is why this age is included in the transition age group.

The overall average age of the patients for which claims were submitted was 9 years of age. The average age of the paediatric group was 7 years, while the average of the transition group was 19 years. The paediatric age group had more than double the rate of service use as compared to the transition age group, meaning that more physician services are being claimed for the paediatric age group (Table 5). Paediatricians had the highest percentage of the total claims submitted (45.51%), followed by Family Physicians (24.02%) (Table 6).

Table 5. Average Age and Number of Claims per 1000 Individuals with CP Submitted for each of the Paediatric and Transition Age Groups

Age Group	Average Age	Claims per 1000 Individuals with CP (per age group)
Age 0 -16	7	367 per 1000
Age 17 -21	19	174 per 1000

Table 6. Percent (%) of Total Claims Submitted by Medical Specialty

Medical Specialties	Percent of Total Claims
Paediatrics	45.51%
Family Practice and Practice in General	24.02%
Ophthalmology	8.32%
General Surgery	4.35%
Orthopaedic Surgery	3.30%
Otolaryngology	2.84%
Internal Medicine	2.76%
Anesthesia	2.02%
Not Assigned	1.32%
Neurology	0.97%
Respiratory Disease	0.86%
Diagnostic Radiology	0.82%
Neurosurgery	0.74%
Obstetrics and Gynecology	0.70%
Urology	0.31%
Psychiatry	0.27%
Gastroenterology	0.23%
General Thoracic Surgery	0.23%
Cardiology	0.19%
Dermatology	0.08%
Genetics	0.08%
Physical Medicine	0.04%
Plastic Surgery	0.04%
Grand Total	100.00%

3.2.2. Descriptive Statistics: Place Dimension

While the location of the patient group does not change, the primary practice location of the physician group does change. A claim submitted by a non-local physician (i.e., a physician with a primary practice address other than Sault Ste. Marie) for a Sault Ste. Marie patient means

that the physician is either a locum or the patient has travelled to another centre to access specialized medical services. Physician practice locations were sorted by LHINs and FSAs.

Claims were submitted by physicians for Sault Ste. Marie patients with CP from all 14 LHINs. The majority of claims were submitted by physicians in the North East LHIN (72.09%) (see Table 7). The data show that people with CP are accessing physician services from diverse geographies. Additionally, besides the North East LHIN, the next three LHINs with the highest percentage of claims are all home to a large tertiary children's hospital (Toronto Central LHIN – Sick Kids Hospital and Bloorview Children's Treatment Centre; South West LHIN – Children's Hospital of Western Ontario; Champlain LHIN – Children's Hospital of Eastern Ontario).

Table 7. Percent of Total Claims of all Medical Specialties by LHIN of Primary Practice Location

Physician LHIN	Percent of Total Claims
<i>North East</i>	72.09%
Toronto Central	16.95%
South West	3.58%
Champlain	3.34%
Central	0.89%
Hamilton Niagara Haldimand Brant	0.58%
Mississauga Halton	0.58%
Central East	0.47%
Waterloo Wellington	0.47%
Central West	0.39%
North Simcoe Muskoka	0.23%
South East	0.19%
North West	0.12%
East St. Clair	0.08%
Not Assigned	0.04%

3.2.3. Service Utilization of Medical Specialties by Patient Age Group

The top ten medical specialties used by each age group are represented in Table 8 and Table 9. Family practice and paediatrics are the two most commonly used medical specialties for both the paediatric and transitional age groups. Both family practice and pediatrics (i.e., general paediatrics) are also considered to be the 'primary care' medical specialties. Therefore, from this

point onward, results will be grouped for comparison between paediatric, family practice, and ‘other medical specialties’ service utilization.

Table 8. Top Ten Medical Specialties with Claims for the Paediatric Age Group

Medical Specialty	Percent of Total Claims
Paediatrics	52.53%
Family Practice and Practice in General	20.63%
Ophthalmology	8.80%
General Surgery	4.31%
Orthopaedic Surgery	3.50%
Otolaryngology	2.22%
Anesthesia	2.13%
Internal Medicine	1.56%
Neurology	1.09%
Diagnostic Radiology	0.85%

Table 9. Top 10 Medical Specialties with Claims for the Transition Age Group

Medical Specialty	Percent of Total Claims
Family Practice and Practice in General	39.57%
Paediatrics	13.26%
Internal Medicine	8.26%
Not Assigned	7.39%
Ophthalmology	6.09%
Otolaryngology	5.65%
General Surgery	4.57%
Respiratory Disease	3.26%
Obstetrics and Gynecology	2.39%
Orthopaedic Surgery	2.39%

Within the paediatric age group, the majority of claims were from physicians located primarily in the North East LHIN, and when drilled down by FSA, of the claims in the North East LHIN, most were from local physicians (67.91%) with less than 2% from other North East LHIN communities. Physicians from outside of the North East LHIN accounted for 30.71% of claims made for the paediatric age group. Paediatricians were the most utilized physician

specialty for this age group with 52.53% of the total claims, followed by other medical specialties⁴ with 26.83% of the total claims, and Family Physicians with the lowest percentage of total claims (20.63%). Within the claims from local physicians, the majority were primary practice physicians for the paediatric age group, while the claims submitted from Other LHINs were from mainly paediatricians and other medical specialties (Figure 4).

Within the transition age group, the majority of claims were from physicians located primarily in the North East LHIN (85.00%), and when drilled down by FSA, of the claims in the North East LHIN, most were from local physicians (81.74%) with 3.48% from other North East LHIN communities. Physicians from outside of the North East LHIN accounted for 15.00% of the total claims submitted for the transition age group. This represents a significant drop in the use of medical specialists from out of town for the transition age group as compared to the paediatric age group. In the transition age group, other medical specialties (47.17%) and family physicians (39.57%) were the most utilized specialties. While paediatric services are still being used for the transition age group within Sault Ste. Marie and minimally in other North East LHIN communities, less than 1% of claims submitted from physicians in Other LHINs are from paediatricians (Figure 5). Use of Family Practice services increases from less than 20% to more than 35% for the transition age group as paediatric service use decreases.

⁴ 'Other Medical Specialties' are considered those from Table 6 that are not labeled as Family Practice or Paediatrics.

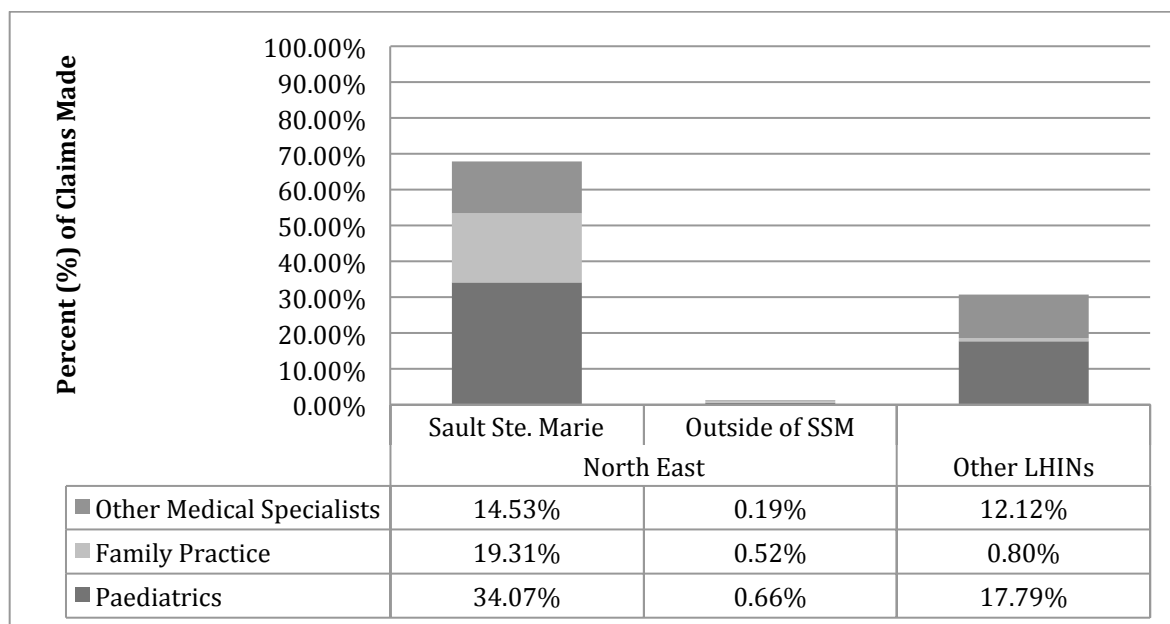


Figure 4. Medical Specialist Service Use by Location for Paediatric Age Group

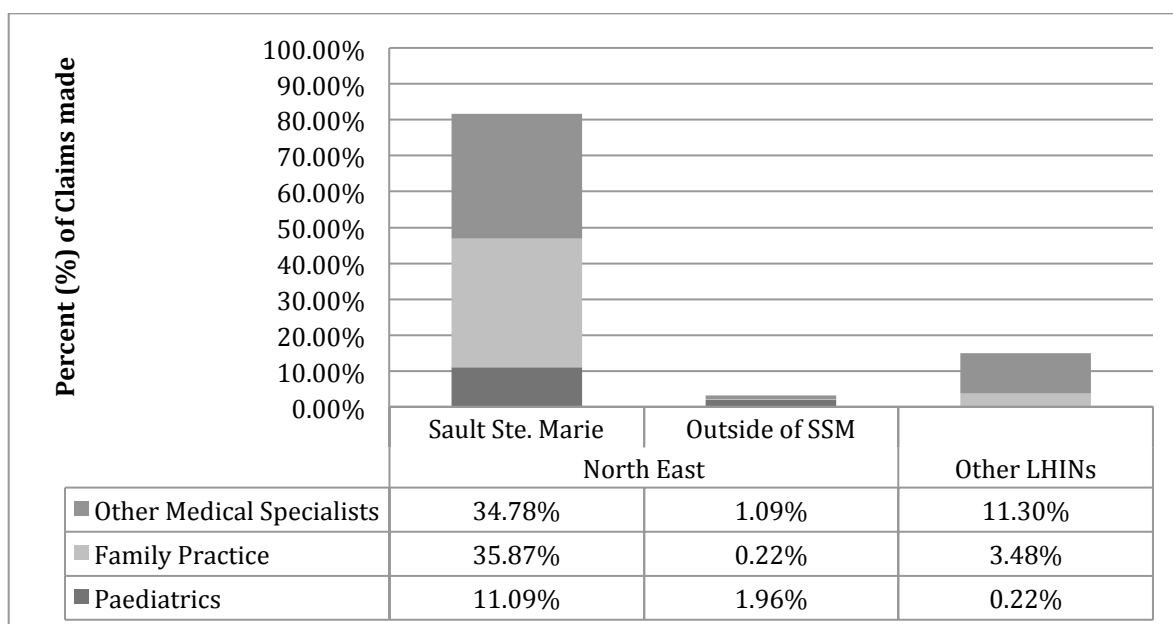


Figure 5. Medical Specialist Service Use by Location for Transition Age Group

There are similarities and differences between the two age groups with regard to the ‘Other Medical Specialties’ service use. The transition age group is no longer using some medical specialties such as cardiology and gastroenterology. However, it is very important to

note that the transition age group utilizes internal medicine, obstetric/gynecological, and psychiatric specialists much more than the paediatric age group. General surgery, otolaryngology, respiratory disease claims are primarily from local physicians for the transition age group, as compared to non-local for the paediatric age group. Also, neurosurgical services, which were mainly accessed within Other LHINs for the paediatric age group, are mainly accessed within the North East LHIN for the transition group (Figures 6 and 7).

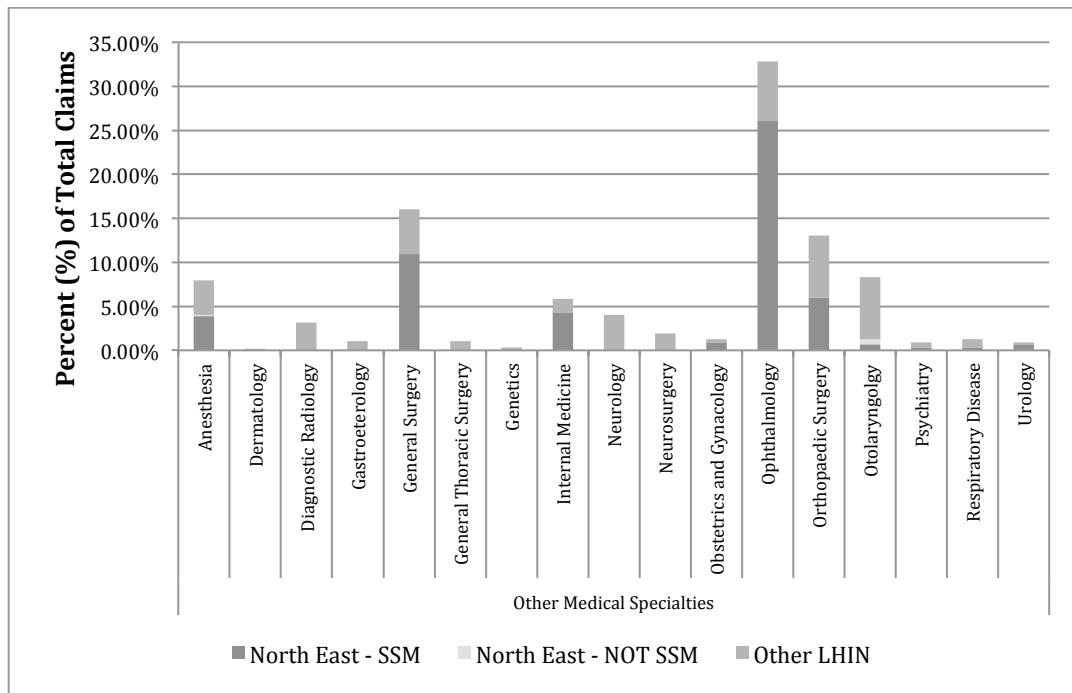


Figure 6. Percentage of Claims from 'Other Medical Specialists' by Location for the Paediatric Age Group

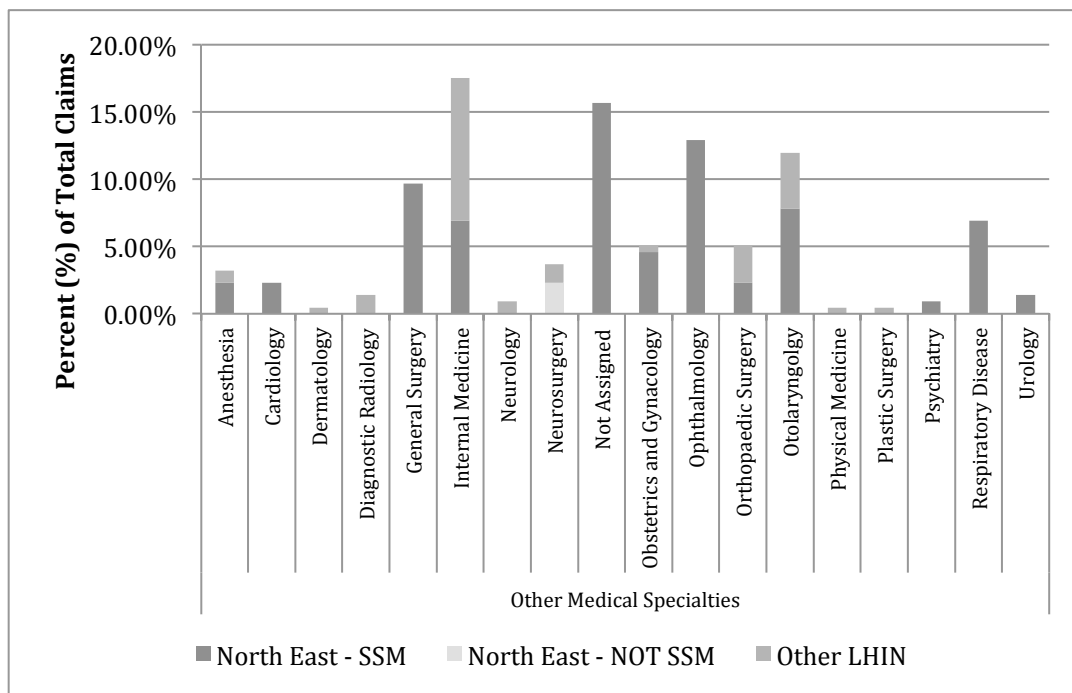


Figure 7. Percentage of Claims from 'Other Medical Specialists' by Location for the Transition Age Group

3.2.4. Summary of Findings from OHIP Claims: Person and Place Dimensions

Analysis of OHIP claims data provided significant insight into the healthcare utilization patterns of youth and young adults with CP in Sault Ste. Marie, Ontario. By splitting claims for physician services into two age groups representing the paediatric healthcare users and the transition-age healthcare users, the analysis showed that following the age of 17, healthcare utilization changes in two respects for young adults with CP. The first change is related to the expiration of paediatric services following the age of 18 (and no new referrals after 17 years of age). The second change is related to the changing healthcare needs of the older age group.

The percentage of claims submitted by general paediatricians although still present, drops significantly in the transition age group. The utilization of ‘other medical specialists’ in the transition age group is also significantly different from the paediatric age group with regards to volume, type of specialty, and location of medical specialists. The transition age group is almost double that of the percentage of claims from ‘other medical specialists’ (47.2% as compared to 26.8%). The transition age group utilizes a very different spectrum of ‘other medical specialists’, which is reflective of their changing conditions secondary to CP and health care needs. Additionally, there is a noteworthy change in the location of all physician services utilized by the transition age group compared to the paediatric age group. While the paediatric age group accesses approximately 30% of medical services from non-local physicians (whether locum, by traveling, or utilizing OTN), the transition age group only accesses about 15% of medical services from non-local physicians. This result is representative of the fact that the majority of ‘other medical specialists’ submitting claims in the paediatric age group are actually specialized paediatricians at larger tertiary centres.

The quantitative findings have revealed that there are more differences than similarities in terms of the type and location of medical specialties used by children/youth (0 to 16 years) and young adults (17 to 21 years) with CP who live in Sault Ste. Marie, Ontario. To gain further understanding it is important to determine how these differences impact the health care transition of young adults with CP in Sault Ste. Marie, Ontario.

3.3. Interviews

Interviews were performed with three family physicians and one paediatrician to gain understanding of healthcare transition of young adults with CP in Sault Ste. Marie. All four participating physicians were male. Total combined years of service was 68 years (mean = 17 years, min = 3 years, max = 26 years). Despite the poor response rate, it is important to note that the participating physicians were representative of the various practice types located in Sault Ste. Marie. There was one family physician from a FHT, as well as three representative of the ADMG each with different characteristics of their independent practice. It should be noted that the 'different characteristics' between the three ADMG physicians cannot be described due to the risk of identifying the individuals; however, the differences between their medical practices do provide the opportunity for a variety of perspectives.

The final analysis resulted in three major themes, each with sub-themes. The main themes were: (1) The Complex Nature of Healthcare Transition, (2) Shared Care and Teamwork, and (3) Physician Tools and Resources (Table 12). In the rest of this section, interview excerpts are used to illustrate the main themes and sub-themes.

Table 10. Themes and Sub-themes for Physician Interviews

Main Themes	Sub-themes
Complex Nature of Healthcare Transition	Implications of an Increased Life Expectancy Severity of CP Broad Spectrum vs. Specialist Expertise
Shared Care and Teamwork	The Importance of Communication Coordination
Physician Tools and Resources	Northern Ontario vs. Southern Ontario Medical Specialist Services Institutional/System Level Solutions

3.3.1. The Complex Nature of Healthcare Transition

Healthcare transition is impacted by many factors that challenge the process of moving young adults from paediatric care to the adult oriented system. Physicians interviewed in this study made special note of the incredible variation of factors that can determine if patients are transitioned or not. Aging, severity of the condition, and the struggle between the need for specialist expertise and a general broad-spectrum approach to care are areas that physicians discussed as being added complexities associated with the decision to transition a young adult with CP from paediatric to adult care.

3.3.1.1. Implications of an Increased Life Expectancy

Family physicians and the paediatrician described the implications of an increased life expectancy and aging in two different contexts. First, the paediatrician described the evolution of the paediatric specialty over the years as modern medicine has changed the life expectancy for children with complex disorders, in reference to the fact that the system is aging:

...see paediatrics in this era as time evolves from say 25 years ago, paediatricians are looking after more chronically unwell children, with chronic illness than we would have 25 years ago, so the percentage of kids with disabilities is much higher because many of those kids may not have lived if they were born in 1960. So, any of the paediatricians

doing a big practice will have a fairly sizable group of children with significant disabilities.

Aging was also described by physicians in the context of the aging child and the changes associated with caring for a young adult with CP as opposed to a child. A family physician described the changes in treatment as children with CP age due to an increase in the complexity of their condition and associated comorbidities:

Generally, as younger children you could be doing medical-type therapies such as Botox injections and then they'll be involved in physio, will need assistive devices. And as they get older they have more complicated needs, like surgical interventions, which is not usually done here, it would be done by one of the orthopods in Toronto.

As they age, young adults with CP require more services and their care can be more complex as a paediatrician describes:

It's is a huge amount of work and although cerebral palsy is a static lesion, the condition progresses and as they get older they are not necessarily less work or less needy, often more so; especially the kids that are quite disabled. It is easier to care for someone who weighs 10 kilos then someone who weighs 60 kilos, just from a mechanical point of view.

While aging is essentially the trigger for transitioning young adults from paediatric to adult services, the increasing complexity of their condition results in a major challenge for physicians in determining if transitioning to adult care is the best care process for the patient.

3.3.1.2 Severity of CP

CP is a very wide-spectrum condition with respect to severity, and as such the comfort level of providing primary healthcare for people with CP is strongly related to the severity of the

condition. Most family physicians are not highly trained in caring for adults with very severe global disabilities, such as with the spastic quadriplegia form of CP. However, there are still some family physicians that prefer to be the primary care provider regardless of severity, but with strong support from the medical specialists available to him/her. One family physician believed most adult providers would agree with this philosophy, and states:

Personally, I would like to be their primary care provider and consult. Again, CP is not that common so everyone's comfort level is different and the level of CP disability would be a major influence. But I think most family physicians would want to be the primary care provider and consult as needed.

However, it is possible that severity of CP may prevent the family physician from being involved as a primary care provider. One family physician described how family medicine physicians may not become involved with the patient until well beyond the paediatric years:

I suspect a more severe case would be picked up right at birth and likely have the paediatrician involved right from the beginning. And we wouldn't likely be very involved in the case until they turn 18. That magical 18.

From a paediatric perspective, severity of CP makes it very difficult to transition patients to an adult provider due to the complex and changing nature of the patients' needs. The paediatrician described how he has several patients over the age of 18 due to the more severe nature of their conditions and the lack of an adult provider with sufficient knowledge and experience to care for such patients:

Well, technically I see people from birth to 18 (well I even see people before birth because I do fetal consults), but anywhere from fetuses to 18 weeks to 18 years. But having said that, we technically can't always transfer care at 18 because there isn't

always the appropriate facility or person to transfer to. We all have, I have several children over 18, several individuals with disabilities over 18, I even have some into their 20s. It is just that they have really complicated needs and the family doctors just don't feel comfortable.

The above quote implies that for young people living with very severe forms of CP, the benefits of transferring to a family practitioner for 'age-appropriate' primary healthcare may be outweighed by their need for specialized medical care.

3.3.1.3 Broad Spectrum vs. Specialist Expertise

Broad-spectrum scope of practice is a core value of family medicine, and is an extremely important component of quality primary health care. However, analysis of the interviews revealed a lack of consensus concerning whether a broad spectrum or specialized approach is more beneficial to a young adult with CP. One family physician described the advantages of broad spectrum medicine for young adults with CP, as well as the advantage of having the paediatrician continually involved:

I think the advantage of being involved with the case would be having the broader spectrum of having to look after the whole family. And understanding and being able to look after the parents and siblings at the same time you gain a full spectrum. However ... those with CP need the whole multi-disciplinary team with the physios and whatever else each patient's needs are, and the paediatricians are already involved in that so the advantage of the paediatrician is to be getting into a system where they have that multi-disciplinary care and specialized.

The above quotation discusses 'broad-spectrum' in terms of not just the individual, but also caring for the whole family, as well as 'broad spectrum' in terms of holistic health care. It is

important to note that this physician in particular practiced as part of a family health team, and the concept of holistic and family-centered care was central to the practice organization. Additionally, some adult providers believed that the wide varieties of complex medical issues associated with CP are more benefited from being involved with a family physician because “with CP, there are a lot of associated conditions so you actually have to be a very broad spectrum physician to treat such a disability”.

However, the paediatrician felt that specialist expertise is still very important in the care of a young adult with CP. This paediatrician described the benefits and disadvantages of maintaining the specialist expertise within the care process of a young adult with CP:

Well there are benefits – that’s why we still have them. The benefit is that we know them, we have all that history. We know the family well, and they often feel comfortable with you. You have the experience, and these kids are often very complicated. So that’s the real advantage. You have a fair group of patients like that, too, so you understand their issues and needs. The disadvantage is that at some point the family doctor is going to inherit this patient. They wouldn’t have the same number, in terms of experience. Clearly there is a disadvantage because you are diluting the expertise, because you can’t be an expert in everything! It makes more sense in most cases that patients with complicated needs are grouped to a few individuals who have the expertise in caring for those cases.

This family physician described how too narrow of a specialized focus can be very challenging for broad spectrum adult providers:

...everyone’s just trying to put their disease process ahead, which is hard for us generalists because if we try to do what each individual group wants us to do, each

patient encounter would be two hours long and we would need one physician for every hundred patients and we don't have that.

A fine balance between broad spectrum primary care and the specialist expertise from the paediatricians and other medical specialties seems to be the most popular opinion with respect to the best care for young adults with CP. It is from these opinions that the next theme, shared care and teamwork, emerged.

3.3.2. Shared Care and Teamwork

The next theme, shared care and teamwork, is broken down into two sub-themes, 'the importance of communication' and 'coordination', that together are the key components of excellent teamwork between providers, the patient and family/caregivers. Shared care and teamwork are extremely important factors that when achieved will lead to smoother transitions for youth and young adults with CP. In fact one family physician stated that strong teamwork skills may help to compensate for fewer resources:

You can have as many good resources as you like, but if they are not going to work as a team then nothing is going to work. On the other hand, you might have very limited resources, but there are people who are devoted to their jobs and devoted to helping their patients and the outcome will be much better.

3.3.2.1. The Importance of Communication

In Sault Ste. Marie, communication between family physicians and paediatricians was described as being very good. Often family physicians needed only to pick up the phone to speak with a paediatrician for support or to discuss a mutual patient, suspicions of a possible CP diagnosis, or for advice on the best practice for specific issues related to paediatric-onset

conditions, such as CP. One family physician described his experiences with communicating with paediatricians regarding his patients with CP:

In terms of paediatrics I was very fortunate with our paediatricians here. I had no problems at all...I was concerned and I just picked up the phone and said you know, I think this guy has CP and it just hasn't been diagnosed yet. I would say great communication. It's the same thing when he was transferring his patients to me, you know he came down to my office and said, listen I have these patients I would like to transfer to you, but they are quite sick, are you comfortable ... I really appreciate this type of direct communication. I think it's great and it is a great benefit to the patient.

Physicians agreed that with all of the challenges and complexities associated with caring for youth and young adults with CP, a large portion of the obstacles may be overcome with good communication between providers and a shared care concept of primary healthcare.

Participating family physicians describe the crucial nature of communication when caring for these types of patients: "I think the key is communication. A doctor talking to a doctor, and one expressing his concerns and care processes and the other asking questions and making sure they are on the same page. Communication is crucial." Communication was described by participating family physicians as essential to doing "the best we can for our patients ...there has to be communication with the patient, between caregivers, and with other healthcare professionals. If there is no good communication we will not be successful".

Following discussion of the complex nature of CP, the variation in severity and the wide spectrum of secondary conditions affecting many areas of the body, there is reason to believe that many different medical specialties as well as allied healthcare workers are part of the care team for youth and young adults with CP. Although communication was described as excellent

between family physicians and paediatricians in Sault Ste. Marie, all four participating physicians noted that there was a significant disconnect with regards to their knowledge of community services available to them and their patients with CP. A paediatrician described the array of community services and other caregivers besides the physician that are utilized by youth and young adults with CP in Sault Ste. Marie:

Well first of all, the physician is only a small part of the caregivers for kids with cerebral palsy. They spend a lot more time with the infant development worker and the physiotherapists and children's rehab center and communications with speech language pathologists, and all that. So the physician piece is probably the smallest piece of the puzzle, but there needs to be someone who takes responsibility for these individuals.

With so many areas of need, it is difficult to access all of the necessary resources within the community. Some community agencies such as Community Living Algoma in Sault Ste. Marie offer many resources and services to people over the age of 18, but these services are only offered to those with profound developmental disabilities. Many individuals with CP do not have cognitive or developmental impairments and therefore would not be eligible for these services (Cans, 2000). Family physicians are not made aware of the services available to their patients and there is very little promotion from community agencies to the physicians. One family physician states, "the problem is that whole area is very complicated, there are many different agencies, and there are not any road maps to go between them either".

Awareness of available community services is not just a challenge for physicians of adult patients with CP. One family physician notes that he had very little contact with the Children's Rehabilitation Centre, the paediatric agency in Sault Ste. Marie that provides various therapies and resources for children and youth with disabilities and their families/caregivers:

I know Children's Rehab is there and I kind of loosely know because I've heard from patients what they do over the years. But I'm not even sure I'd know how to refer to them or how to access any information or flow of information between caregivers, which is kind of sad.

On the whole, there is a divide between the medical group and the services available in the community. One family physician explains the disadvantages resulting from this disconnect for persons with CP:

I think the disadvantages are really the resources available. There are really limited resources. I think the access in the community for disabilities are better; I think there is a better awareness for it. But still lots of limits to people's access in the community. We have a pretty good in-home assessment program to let the people know what they could use in their home to make things easier for them, but you know how much resources financially to do this are limited.

3.3.2.2. Coordination

Coordination was a common topic of discussion with both family physicians and paediatricians, and that a lack of coordination challenges the success of teamwork and shared care. Physicians reported having a hard time keeping track of which resources and community services have been previously accessed, as well as which medical specialists or rehabilitation services previously treated the patient. Some participants note that for physicians on a shared electronic medical record system, this challenge is lessened. However, community services, allied health care, as well as a large portion of the physicians in the city are not on a shared medical record system. The ADMG physicians at the Group Health Centre are fortunate to have

access to a centre-wide electronic medical record system, and due to the fact that the majority of specialists are part of the ADMG, family physicians practicing here are at a slight advantage.

A participating family physician described how a coordinator could drastically improve consistency and continuity of care:

We could do much better with coordinating the care. If there was a coordinator who knew the patients well, particularly for the patients I have recently accepted, if there was someone I could call who knows the history. It provides a consistency to the care, rather than a bunch of different caregivers.

A participating family physician notes that they often do not know what is available with respect to community resources, nor do they have the time to locate all of the services available for adults with CP, which is where a coordinator would be extremely helpful:

I think the best thing would be a coordinator! And depending on the community you are in you could contact. And that goes for any disease, but this one especially. I have a patient with CP and I wish I could call someone and they could tell me “OK, these are the resources available that we could access”. Because I think physicians have a limited knowledge of what is really out there.

Another participating family physician suggests that it may be the responsibility of the paediatrician to line up the necessary care providers for a young adult with CP who is transitioning into the adult healthcare system:

These are very complex patients and if you are a paediatrician looking after a child it is sort of your responsibility that there is a continuance of care and to properly do it you basically have to find a physician for this patient. Otherwise you’re just discharging from

paediatric practice expecting someone to pick up the patient and that's not the way it should be.

However, paediatricians have just as little knowledge of the extent of community services available to adults with CP as the adult providers. The variability and complexity of CP, need to coordinate community resources, medical specialties, and rehabilitation and other therapeutic services means that all care programs and services will need to be arranged for each unique young adult with CP. This paediatrician describes how a coordinator could play the role of linking the paediatric world with the adult-oriented world:

...if you have CCAC [Community Care Access Centre] with a coordinator for this, and they hook them up with Community Living Algoma, or maybe it's physio they need or an orthotist, or this or that. But they would have all this information and they would run, not necessarily a "program" but link the services that suddenly disappear off the face of the earth when the patient turns 18.

There is an obvious disconnect between primary care physicians and the available services and resources within the community that are of benefit to people living with CP. The physicians interviewed in this study all mentioned that having a coordinator available to eliminate the gap would be extremely beneficial to their primary care practice. During the interviews, none of the physicians spoke of one specific community resource or service they would utilize for an adult with CP, although all physicians spoke of the Algoma Children's Treatment Centre with regards to referring children with CP. This speaks to the lack of available services or the awareness of available services for adults with CP in Sault Ste. Marie, and the opportunity for improved coordination to close this gap. A coordinator is not currently available

in Sault Ste. Marie, so physicians interviewed in this study spoke to their use of other tools and resources to aid in the primary care of patients with CP.

3.3.3. Physician Tools and Resources

Physicians regularly use different clinical tools such as order sets, which provide a list of best practice tests and procedures to follow for a specific diagnosis, as well as clinical protocols and health watch tables. Physician resources range from these clinical tools to the use of specialized physicians for consultation or referral, which provide more detailed and focused care for a particular disorder. With CP being a condition with such a wide spectrum of variability with regards to severity as well as associated conditions, family physicians and paediatricians often require special resources to provide their patients with the best primary care possible. Family physicians and paediatricians describe the differences between Northern and Southern Ontario in accessing tools and resources to assist in caring for their patients with CP, as well as the need to access various medical specialties throughout the lifespan. Physicians also discussed the various institutional and system level solutions that could assist them in providing smoother transitions and quality primary health care for people with CP across the lifespan.

3.3.3.1. Northern Ontario vs. Southern Ontario

The interview script paid particular attention to physicians' perceptions of differences between northern Ontario and southern Ontario with regards to primary and specialist health care, as well as transition processes for youth and young adults with CP. During the interviews physicians continued to reference northern Ontario synonymously with Sault Ste. Marie, and vice versa. It should be noted that Sault Ste. Marie was the only Northern Ontario city that each physician had previously practiced in. However, all four physicians had experience practicing medicine in Southern Ontario cities be it through medical training or fully-licensed practice.

Northern Ontario differs in many ways from Southern Ontario, especially with regard to access to specialty medical services (Wenghofer, Timony & Pong, 2011). Aside from the five general paediatricians practicing in Sault Ste. Marie, there are no paediatric specialists available to children and youth with CP at a local level. However, Sault Ste. Marie and much of the province utilize locum services as well as the OTN.

As well as access to medical specialties, Northern Ontario has a lack of specialty clinics, tertiary centres and specialized community resources. One family physician discusses the differences between northern Ontario and southern Ontario:

I think it's really just the quantity of care you can get in Southern Ontario. So you have clinics in the bigger centers so people have easier access to go to these big clinics and to talk to them by telephone. They have better support systems. I mean our support system outside of the medical community with the community care programs isn't as...well there aren't as many resources. So I think that's the main thing. And really that goes across the board for most diseases; it's not just unique to CP.

When asked to discuss the difference between northern Ontario and southern Ontario with regards to the care processes for people with CP, a paediatrician hypothesized that based on the vast amounts of highly specialized paediatricians, that patients with CP in Southern Ontario would more likely be under the primary care of very specialized physicians rather than primary care providers (paediatricians or family physicians alike):

My suspicion is that it [care in southern Ontario] is more, at least as much if not more, in the hands of the paediatricians, given that there are more specialists. A lot of the worst kids with CP would come through CPRI [Child and Parent Resource Institute] in London, which is affiliated with the university. So in that circumstance my suspicion would be

that there is even more of a tendency for those kids to be looked after by the specialists, and not even the general paediatricians as much as a physiatrist or paediatric developmental person. So in that case you've gone one step further, and the general paediatrician wouldn't even look after those kids.

Although more highly specialized physicians are available in southern Ontario at the larger clinics and tertiary centres (see www.cps.ca), one family physician explains, "as long as there is a physician who is willing to see the patients, I don't see why there should be a difference. I came from London, Ontario and there is a shortage of physicians there, too".

3.3.3.2. *Medical Specialist Services*

After noting that the majority of the more specialized medical services that include physicians and health care professionals trained in caring for people with CP are in Southern Ontario, physicians emphasized that the specialized services are still heavily used by patients that reside in Sault Ste. Marie, be it through locum services, OTN or by traveling to a larger center:

We often use our visiting neurologists...and there are CP clinics we would refer them to depending on their level of disability and would coordinate that through telemedicine. I mean ideally for us it would be great if we had a CP specialist come up here and run a clinic, and in the past they have done that, but it's difficult because we don't have the patient volume to justify that.

Of the medical specialties that are available in Sault Ste. Marie, such as orthopedic surgery, some patients with CP will still need to travel to a larger centre for surgeries or other procedures related to their CP diagnosis. The low volume of people with CP in smaller cities such as Sault Ste. Marie means that the local surgeons do not perform enough of the specialized surgeries associated with CP treatments to become experts. Therefore, surgeons in other larger

centres who perform these procedures more often are better suited to care for Sault Ste. Marie patients when it comes to a specialized medical issue associated with CP. One family physician described this process:

Another patient I have was recently assessed by an orthopedic surgeon in Ottawa and treated there. This patient had some significant issues with muscle contractures secondary to cerebral palsy. We have great orthopedic surgeons here in the Sault, but their respective practices do not include these specialized areas. So the patient was treated in Ottawa.

Although traveling long distances to receive specialized medical care may seem like a major disadvantage for people with CP in Sault Ste. Marie, one family physician notes that although “surgeries often have to be done out of town because they are a bit specialized surgeries...that’s fair enough, people accept that I think”.

Accessing specialized medical services from locum physicians or by traveling to larger centers is a fairly simple process when patients are at the paediatric level; however, this is not the case for youth and young adults with CP. At 18 years of age, all of the specialized services accessed through the paediatric system are no longer available and adult physicians and healthcare services will need to be arranged. A paediatrician described the expiration of paediatric services:

The one issue that is really important from a paediatric perspective is that when we continue with the care of that patient over 18, all of our supports for them medically are gone. So say they have a severe seizure disorder and they are seeing the paediatric neurologist – gone! They won’t see them anymore. Yeah, so these kids have all sorts of problems right, scoliosis, hip dysplasia. Suddenly, you can’t send them to see your

person for orthopedics that you use because the patient is 17, and none of the [adult] orthopedics in town feel comfortable with this case, and now you don't know where to send them, or who to send them to. Or, like there is no neurologist...we have a visiting paediatric neurologist and I can send kids to London to see a paediatric neurologist, but I can't send an 18 year old to see my visiting paediatric neurologist. We have some adult visiting neurologists, so you might be able to do that. But, suddenly in a lot of situations you are out of your comfort zone because the same people that were at one time supporting them, like the Children's Rehabilitation Centre, 18 is their cut off. They don't say "well there is no place to send them, we're going to keep them". The specialists don't do that. Actually if you are a specialist in southern Ontario, you aren't allowed to see them, so you have to send them to adult providers.

The expiration of paediatric healthcare services at 18 (no new referrals after 17 years of age) is what leads to the largest gap in healthcare services through the transition from paediatric to adult healthcare. While there are primary healthcare providers in each system (i.e. paediatricians and family physicians), there are very few adult medical specialists with the experience or training in providing care and treatment to adults with childhood-onset conditions, such as CP. The knowledge of a general lack of knowledge and experience in caring for adults with CP lead the interviews into discussion of possible solutions coming from the institutional or system level.

3.3.3.3. Institutional/System Level Solutions

Physicians discussed the challenges at a system level that contribute to gaps in primary care following transition from paediatric to adult healthcare. A paediatrician notes that "there needs to be a way of systematically looking after these children afterwards. It isn't even very

well developed for the children, let alone adults”. The paediatrician also spoke to the consequences that arise when patients with CP fall through the cracks:

There is no way right now of taking care of their needs. The problem with all of this is that they [people with CP] may fall through the cracks and then it becomes very expensive. They end up in hospitals, emergency departments, and now we’re talking about a decent cost-saving care model. And the family doctors don’t want to do it...When the attention to care is not given, they end up lost, and it gets expensive. I’ve had several kids even with attentive care in hospital. Without proper maintenance, it’s just like your car if you don’t take your car in the oil runs out and the whole thing breaks.

Family physicians discussed various tools that could be implemented from a system level perspective such as widespread electronic medical record systems:

...another tool would be the electronic medical record for the patient...that is accessible by anyone within the circle of care that the client so desires, rather than having these isolated blocks of information that one caregiver can’t read.

In addition to the electronic medical record that is accessible across the spectrum of healthcare providers, family physicians discussed the consistent implementation of best practice guidelines, health watch tables and other checklists across the system:

I think an easy to use, kind of guidelines for lack of a better word, would be useful. But, I don’t think we have any of those. I mean these diseases that aren’t as common, are the ones that could really benefit from those kinds of tools. The common ones we have a lot of proof of treatments working and everything, but we sort of struggle with where to go next with the less common diseases.

However, the widespread implementation of clinical guidelines is not a new approach for primary care physicians, and one family physician warns of the dangers in becoming too focused on the diagnosis of CP:

They [guidelines] do speed up the process, but there still has to be a physician who approaches a patient directly and treats the patient as a separate entity. We have to remember we treat the patient not the disease. With some checklists we might treat the CP not the patient with CP. But it might be good as a reminder, so we don't forget about certain issues that could come up.

It was discussed in length that patients with CP require a lot of time and attention, which is extended depending on the severity of their conditions. A paediatrician describes the implementation of financial incentives at the system level with regards to specialized billing claims:

Well, there might be from an institutional point of view, making it financially remunerative for physicians. Maybe have complex care code, from an OHIP standpoint. They did it with diabetes. And also with certain people with chronic problems you get... well like if I see someone with diabetes you get this extra code you add on and it gets you that extra 30% or something. Obviously, reimbursement is an issue...if I go in there with a kid with spastic quadriplegia, I could be in there for an hour and a half – its financially very unrewarding, but it's part of what you do. Some things you can do quickly, but you get paid the same.

The addition of financial remuneration for primary care providers may increase the willingness of family physicians to accept transitioning young adults with CP into their practice.

However, a paediatrician describes what may be a more cost effective solution to providing primary healthcare to transitioning youth and young adults with CP:

This would be the perfect area of specialty for nurse practitioner. They have the time.

One of the things with family doctors is that they don't have time to do complicated things. Doing complicated things is not profitable for them, doing a bunch of little things is way better...you can't see an adult with cerebral palsy in 10 minutes in your office, you just can't. So you get a nurse practitioner and she has 6 spots a day and she sees 6 of these individuals, and spends an hour with each of them. And now this person has the expertise and she works with a bunch of other providers and resources. And this is what would work the best. They'll do a better job, and they'll have more time. They will do all of the stuff they are supposed to, and they will do it every time. So optimally, that is a way better model than a family doctor model. That would be a great idea. And it would be easy and then you maybe transition to her at 16 or 17, start sharing care for a couple of years, and you could do that for all developmental disabilities, not just people with CP because there is a raft of people out there and there will be more and more and more and there is no way of looking after them.

The suggestion of using nurse practitioners (also known as advanced practice nurses), as the primary care providers for transitioning young adults with CP is an innovative solution that may prevent patients transitioning from paediatric care from becoming lost in the medical system, and may also solve the issue regarding lack of coordination of all required health care services.

3.3.4. Summary of Interviews

Interviews of primary care providers (family physicians and paediatricians) in Sault Ste. Marie resulted in the emergence of three major themes related to primary healthcare and

healthcare transition of youth and young adults with CP. Physicians stressed that healthcare transition of young adults with CP is extremely complex in nature and is dependent on multiple factors, including the implications of an increased life expectancy, the severity of CP, and the struggle as to whether a broad spectrum or highly specialized focus and approach is more beneficial. Due to advancements in medical and surgical technology and treatments, children diagnosed with CP are living well into adulthood and as a result there are certain implications and unforeseen challenges that significantly affect their primary care. The paediatric system has had enough time to develop and provide the necessary medical care and support services to best care for the entire spectrum of children with CP, from mild to severe disabilities. However, the adult healthcare system is not yet evolved to support a growing population of adults with complex childhood-onset disabilities, such as CP. Therefore, until a system is in place to provide adults with CP the spectrum of services they require, both paediatricians and family physicians struggle to decide on the best process for providing appropriate primary care to these individuals.

While the system and its processes remain fragmented, physicians noted that teamwork and shared care play a significant role in ensuring that young adults with CP are not neglected with regards to access to primary healthcare following the expiration of paediatric services. Discussions of support services available in the community led to the realization that there is a significant disconnect between physicians and many of the services and external supports that are of substantial value in terms of living with CP (e.g., respite care, financial support). They noted that often these services are more easily coordinated in the paediatric system, while parents and caregivers play a significant role in care. However, as young adults age, they may seek greater independence or become more difficult to care for without increased professional

support. Additionally, new secondary health conditions may arise or existing issues can progress, and the adult system is not equipped to coordinate these needs.

Much of the research on healthcare transitions is based in larger communities with tertiary children's hospitals and established programs. It was important for the purpose of this case study in Sault Ste. Marie to provide insight as to how primary healthcare and transition of youth and young adults with CP occurs when medical specialists and services specific to CP are not available at a local level. The physicians interviewed in this study emphasized their innovative use of resources and tools to circumvent to the best of their ability the challenges associated with limited access to specialized services. The use of locum physicians and the Ontario Telehealth Network were described as essential to obtaining access to highly specialized physicians, which is extremely important for providing Sault Ste. Marie patients with the best care possible. However, physicians stressed that highly specialized medical care is not the 'be-all and end-all' of primary healthcare for youth and young adults with CP. Participants emphasized that broad-spectrum, family-centered, and preventative maintenance care is essential. Therefore, discussions of SIFP initiatives were not well received or strongly promoted by the participants (at least not in a community such as Sault Ste. Marie where access to healthcare is already limited). Dialogue surrounding the changing face of family medicine in Ontario also sparked a paediatrician to suggest the use of a nurse practitioner to provide primary healthcare for youth and young adults with CP.

3.4. Chapter Summary

An essential component to the case study methodology driving this research was to analyze multiple sources of data to ensure rigor and stress the complexity associated with healthcare transition of youth and young adults with CP in Sault Ste. Marie, Ontario. Together

the quantitative and qualitative data emphasize the importance of looking beyond the expiration of paediatric services to examine the types of services and where they are located. Most of the interviewees talked generally about the specialty medical services available to the paediatric population compared to the transition-age population. However, only the OHIP claims data provides an exact picture about how the types of medical specialties change.

Another topic that can only be understood with the combination of the quantitative and qualitative data is the geographic variation and change in the primary health care services used by the transition age group. The OHIP claims data shows that the transition age group is still receiving medical care from practitioners outside the North East LHIN, even though those medical specialty areas such as orthopedics and internal medicine exist in the local area. The findings from the interviews reveal that patients may still have to travel to larger centers for certain procedures as the local practitioners have not performed enough of the procedures to develop an expertise.

The above are two examples where both types of data are crucial to understand the complexity of the primary health care transition of young adults with CP in Sault Ste. Marie, Ontario. The next chapter examines not only how a case study approach and complexity theory contributed to this research but also how this research can contribute to the theoretical and clinical knowledge of primary health care transition.

Chapter 4: Discussion and Conclusions

4.1. Discussion

Despite substantial quality improvement efforts, position statements and guidelines, healthcare transition for young adults with childhood-onset conditions such as CP continues to be an area of growing research due to a considerable decrease in access to primary healthcare in the adult medical system. Questioning why current approaches are not making true changes draws attention to healthcare organization as a potential source for answers. Anderson et al. (2005) bring together the case study method and complexity science to suggest new ways to study healthcare organizations. While the case study provides a method for studying systems, complexity theory suggests that keys to understanding the system are contained in patterns of relationships and interactions among the system's agents. The findings of this thesis contribute to two main issues discussed in the literature: (1) healthcare transition models for youth and young adults with childhood-onset disabilities, and (2) the concept of approaching healthcare research from a perspective of complexity theory.

Through analysis of quantitative data from the MOHLTC and interviews with a paediatrician and three family physicians in Sault Ste. Marie, Ontario, this thesis study has identified several areas of interest with regards to the complexity of the healthcare transition of youth and young adults with CP. This chapter will discuss the study findings from a complexity science perspective. The research questions and primary goals of this thesis were to: (1) determine the similarities and differences of medical specialist service utilization between people with CP who are eligible for paediatric healthcare services (ages 0-16 years of age) and those who are in the transition phase (17-21 years of age); (2) the barriers and challenges that physicians face when transitioning young adults with CP; and (3) innovative solutions to closing the transition gap.

The next three sub-sections provide the answers to the three research questions driving the thesis. Research question 1 was answered through the analysis of quantitative data from the MOHLTC OHIP Claims Database (see section 4.1.1). Additionally, research questions 2 and 3 were answered through analysis of semi-structured interviews (see sections 4.1.2 and 4.1.3, respectively).

4.1.1. Utilization of Medical Specialist Services Across Age Groups

In Ontario, the ability to access paediatric services expires when a patient turns 18 years old, and new referrals to paediatric specialists cannot be made following the patient's 17th birthday (Ministry of Health and Long-Term Care, 2013). Data received from the MOHLTC OHIP Claims Database provided the opportunity to illustrate the patterns and changes in medical specialist utilization that occur throughout the paediatric and transitioning young adult lifespan. The expiration of paediatric services is especially prevalent in the analysis of this data, and the challenges this poses is shown in the interview data. However, changes in service utilization also reflect the shifting medical needs as youth with CP age and their associated conditions change. Much of the literature pertaining to the expiration of paediatric services after 18 years of age leads to the conclusion that patients are unable to access specialized medical services following transition to the adult healthcare system. However, guided by the perspective of complexity theory, it is important that case studies within complex adaptive systems are highly sensitive to patterns (Anderson et al., 2005).

It is important to note that in Ontario, physicians are capable of having more than one medical specialty (Ministry of Health and Long-Term Care, 2013). For example, many paediatricians also carry training in other highly specialized areas, which labels them 'paediatric specialists' (e.g., a paediatric orthopedic surgeon) as opposed to a general paediatrician.

However, in terms of billing to OHIP for medical services, physicians can only bill based on one specialty (Ministry of Health and Long-Term Care, 2013). For example, a paediatric orthopedic surgeon will submit claims based on the specialty code ‘orthopedic surgeon’ rather than paediatrician. Therefore, we can assume that a large majority of claims submitted by ‘other medical specialists’ for patients in the paediatric age group are actually from paediatric specialists, whereas claims submitted for patients in the transition age group are from adult medical specialists.

There are two dimensions embedded in the analysis of OHIP claims with reference to the changes in medical specialty utilization across the age groups. The first is the place dimension indicating the location of the physician, and second person dimension focuses on the medical specialty of the physician. Although the majority of claims submitted for patients in the paediatric age group were from local physicians, more than 30% were from other LHINs, which is double that of the transition group. Physicians with a non-local primary practice location who submit claims for care of local patients are either locum physicians, who are often visiting from tertiary centres with highly specialized skill-sets, or their patients are traveling to their primary practice location to receive specialized medical care. Because the majority of these specialized physicians are located at paediatric tertiary centres, it is reasonable that the number of physician claims from other LHINs decreases for the transition age group as eligibility for paediatric services expires.

While claims from paediatricians decrease for the transition age group, the percentage of claims for ‘other medical specialties’ more than doubles as compared to the paediatric age group. As previously mentioned, the shift in the types of medical specialties utilized across the age groups is indicative of the expiration of paediatric services, but the findings from this study are

also highly revealing of the change in service needs as youth with CP age into adulthood. The most notable shift in medical specialist utilization is the significant increase in use of internal medicine specialties for the transition age group. In the adult healthcare stream many of the highly specialized physicians experienced in caring for children with CP do not exist; therefore, internal medicine specialists become the most utilized medical specialty for the transition age group. There is also an increased usage of obstetric and gynecological specialists, as well as psychiatric specialists. The transition age group, as compared to the paediatric group, still uses many of the same medical specialties such as general surgery, otolaryngology, and respiratory specialists; however, the analysis shows that claims for these specialties are almost entirely submitted by local physicians as opposed to physicians from other LHINs seen in the paediatric age group. While the literature focuses mainly on the expiration of paediatric services as the focus for healthcare transition problems (see Cooley & Sagerman, 2011; Murphy, Carbone, Council on Children with Disabilities, & American Academy of Paediatrics), the findings from this study suggest that the changing health needs of young adults with CP, and therefore the change in required medical specialists, should also be of focus in future healthcare transition research.

4.1.2. Challenges and Barriers of Healthcare Transition

The wide variety of medical specialist services alone for which OHIP claims are made for patients with CP illustrates the complex nature of CP with regards to the multiple secondary conditions that arise across the lifespan. Analysis of interviews with paediatricians and family physicians in Sault Ste. Marie found that the outcomes of living longer and aging with CP, the severity of the condition, and the struggle as to whether broad spectrum or specialized medical expertise is the best approach to primary care of young adults with CP all contribute to the

complex nature of healthcare transition. The complexity of CP results in many challenges and barriers to implementation of a smooth transition to adult care.

As described by Viner (1999), healthcare transition should be an educational and therapeutic process rather than a single event. This case study is guided by complexity theory such that research observations that target patterns of relationships, interactions, and processes over time become the keys to understanding a system (Anderson et al., 2005). Therefore, discussion of the interdependent relationship of paediatricians and family physicians, as well as the challenges or barriers they face with regards to transitioning young adults with CP provides important information for understanding the event as a whole (i.e. for understanding the healthcare transition process).

Anderson et al. (2005) note that through complexity theory we recognize that it is the interdependencies and interactions among the elements of a system that create the whole. Thus examining the interdependencies among the elements (i.e. the physicians), and the unity of the system itself, provides critical insights for understanding healthcare transition of youth with CP. Paediatricians and family physicians are interdependent elements in the system of healthcare transition. That is to say they are mutually dependent on each other; in order to transition to an adult primary care provider, a pediatrician requires an available family physician willing to accept the patient with CP, and vice versa. By interviewing both paediatricians and family physicians, this study was able to incorporate interdependency as an extension of complexity theory into the case study, resulting in a better understanding of the challenges faced by both specialties.

A major characteristic of complexity theory is that of unintended consequences (Anderson et al., 2005). New technologies and advanced medical treatments for CP have led to

longer life expectancies for those diagnosed with the condition. However, improved healthcare in the paediatric stages of life resulted in a population of young adults with complex medical issues in need of adult primary healthcare from a system that is not trained or experienced in caring for them (Young, 2007). Both paediatricians and family physicians discussed this issue as being a challenge to implementing effective healthcare transitions. Paediatricians now have more patients with severe disabilities and complex medical conditions, resulting in an evolution of paediatric practice. A paediatrician interviewed in this study indicated that today most general paediatricians do very little primary care for healthy children and youth, as they are required to focus on the increasing population of complex patients in their practices.

Aging youth and young adults with CP experience different secondary or associated conditions throughout their lifespan (Rosenbaum & Rosenbloom, 2012), which results in a shift in specialist service needs. Physicians interviewed described the differences in medical treatments based on the age of the patient, and stressed that not only will the required medical services change, service usage will more than likely increase as they age. Service usage in this sense is not exclusive to medical care, but also includes assistance for transition to various levels of independent living from a societal perspective such as financial assistance for respite care, in-home environmental accessibilities, and assistive devices. The qualitative data showed a strong interactional component between paediatricians and family physicians with regards to communication and coordination of care transfers. However, this was not the case with regards to accessing community resources and services. In fact physicians discussed a ‘disconnect’ in terms of knowledge and communication with non-physician services, and noted this as a significant barrier. With the knowledge that both medical and non-physician service requirements are likely to increase as young adults with CP age, a disconnect between primary

care providers and access to these services poses a major challenge and is an important area for future research.

Chronologically, increasing age is the trigger for implementation of healthcare transition of young adults with CP. However, physicians noted that severity of CP plays a very large role in determining if transition to adult primary care is the best choice for the patient. While the broad-spectrum care provided by family physicians is essential to quality primary health care at the adult level, individuals with moderate and severe forms of CP may benefit from the concentrated expertise that is typical within the paediatric system.

The concept of interdependencies was discussed previously with regards to the mutually dependent relationship between paediatricians and family physicians in the transition of primary healthcare to the adult system. Anderson et al. (2005) state that in complex systems actions are interdependent with actions, ideas are interdependent with ideas, and most importantly, actions are interdependent with ideas. Physicians discussed in detail the importance of teamwork and shared care in implementing a smooth transition to adult care and providing quality primary healthcare to young adults with CP. However, the physicians noted that there are many times that adult providers are not included in the care process until after paediatric services expire, and that perhaps if there was more shared care between paediatricians and family physicians, then adult primary care providers may be more comfortable with taking on patients with complex childhood-onset disorders, such as CP. Therefore from the perspective of complexity theory, “when we see either a discrepancy or a consistency between ideas and actions, this is a cue to search for and describe the underlying interdependencies” (Anderson et al., 2005, p. 4).

4.1.3. Innovative Solutions for a Brighter Future

Following discussion of the array of challenges and barriers physicians are presented with, the paediatricians and family physicians provided their opinions on various solutions to the transition gap that were guided by the current literature, such as implementation of clinical practice guidelines, checklists or health watch tables and tools, as well as the option of family physicians moving towards focused practices. Case study research performed from the view of complexity science advises that the researcher play close attention to the observer roles, as responses to the researcher can provide considerable information about the nature of the system itself. By introducing examples of solutions already discussed in the literature, the researcher was able to better understand the system (i.e., healthcare transition) by studying the physicians' responses. While all of the physicians acknowledged that practice guidelines and checklist-style tools to assist in the care of individuals with CP across the lifespan may be beneficial as a gentle reminder, some physicians discussed the negative consequences of using these rigorous tools. They noted that, while protocols may speed up the appointment process, there is significant danger of them resulting in physicians focusing too much on treating the disease and losing sight of the patient focus.

There was a similar response with regard to a shift towards family practice with a specialty focus, as introduced by the college with SIFP. Most of the family physicians interviewed did not see the benefit in a focused general practice, and noted that in a community such as Sault Ste. Marie, there is a limited volume of most specialized conditions to justify focusing practice. They also expressed concerns that due to the lack of generalists available, the SIFP initiative could significantly affect access to comprehensive primary health care.

Because the nature of a complex adaptive system emerges through self-organization and has the property of equifinality (i.e., having the same effect from multiple events), when more than one case is studied, more than one successful configuration is likely to be found (Anderson et al., 2005). In health care, much value is placed on identifying and disseminating ‘best practices’ (Plsek & Greenhalgh, 2001; Viner, 1999). Complexity theory suggests, however, that there may be more than one way for organizations to be successful. In research, if we seek that one best answer we will probably find it. Research that is open to more than one way of looking at situations however, will lead to more useful knowledge. There is likely to be more than one successful process, structure, or configuration of processes and structures (i.e., patterns of organization) within any complex adaptive system. Because case studies are designed first to describe the uniqueness of each case, it is a method that is well suited to finding multiple successful patterns (Anderson et al., 2005). A paediatrician interviewed in this study introduced the option of using an advanced practice nurse (nurse practitioner) model instead of the highly researched family physician model (see Reiss & Gibson, 2002; Reiss, Gibson & Walker, 2005) for transitioning young adults with CP from paediatric to adult primary care. The recommendation was based on the notion that nurse practitioners are a much more cost-effective solution and have more opportunity than family physicians to provide more focused, yet still comprehensive primary care to youth and young adults with childhood-onset disabilities.

4.2. Linkages and Contribution to the Literature

A good proportion of the findings from this thesis study were in line with the literature, including that the expiration of paediatric services at age 18 is a significant challenge to providing appropriate primary and specialized healthcare for adults with CP. The findings also

provided unique results that can contribute to further understanding of transition models and complexity theory.

4.2.1. Transition Models

A number of programs across Canada have been implemented in response to the surge of research and awareness surrounding healthcare transition of youth and young adults with childhood-onset disabilities (Grant & Pan, 2011). These initiatives are often based on theoretical models, most notably the Shared Management Model (Kieckhefer & Trahms, 2000) (see Figure 1) used at Sick Kids Hospital and Bloorview Kid's Rehabilitation Hospital in Toronto, Ontario. A critique noted in earlier discussion of the shared management model was that of the missing link of a shift between providers. The findings of this thesis study contribute to the redesign of the shared management model framework to include the communication and coordination between paediatric and adult healthcare providers. Physicians participating in this study stressed the importance of teamwork and shared care, communication, and coordination across healthcare providers. Therefore, it is proposed that the Shared Management Model be altered to include a shift in responsibility from paediatric to adult provider, as well as from paediatric provider to the youth.

In addition to the inclusion of a shift of responsibility between providers, the changing roles identified in the Shared Management Model require further description to emphasize what is meant by the resource, consultant, supervisor, and manager roles. The Shared Management Model is used as a foundation for the development of transition programs, but it has great potential for outlining the graduated healthcare transition of youth on an individual basis with the definitions of the various roles changing depending on the abilities and independence level of the young adult. In a recent report outlining consideration for transition to adult healthcare, the

Shared Management Model was discussed and it was noted that the transfer of knowledge throughout the transition must take several factors into consideration such as chronological age, stage of development and any cognitive, physical, maturational or psycho-social issues that may impact the person's ability to acquire knowledge and assume responsibility of care (Provincial Council for Maternal and Child Health, Child and Youth Advisory Committee, & Transition to Adult Healthcare Services Work Group, 2011). Ontario's framework regarding chronic disease notes that in order for the healthcare system to effectively respond to those with chronic conditions, individuals and families need to play an active role in their health, have the support to manage their conditions as much as possible, and in turn, support for individual self-management needs to be an integral feature of healthcare organizations (Ministry of Health and Long Term Care, 2007).

4.2.2. Complexity Theory and Healthcare

This thesis sets a precedent for understanding healthcare transition from a complexity theory perspective. The case study approach used in conducting this research provided a strategy for studying a highly integrated system. Complexity theory is a useful companion to case study because it simultaneously fosters an attitude of attention to emerging patterns, dynamics, and comprehensiveness while focusing attention on defined system properties (Anderson et al., 2005). The theory suggests that the keys to understanding the system are contained in the patterns of relationships and interactions among the system's agents (Anderson et al., 2005). As such, complexity theory provides a starting point to begin the daunting task of studying processes with the health care system as an integrated whole. Designed, analyzed and described from a complexity science perspective, this thesis study emphasizes the standpoint from Anderson et al. (2005) that the case study strategy can contribute appropriately at any level of

knowledge development including exploratory, descriptive or explanatory purposes, as well as testing a theory. The analyses and findings of this study explored physician perspectives of healthcare transition, described medical service utilization patterns amongst youth and young adults with CP, explained the main reasons behind the gaps in primary care from paediatric to adult systems, and demonstrated that in order to best understand healthcare transition the research must be performed from a complexity theory perspective.

The complexity theory extension of interdependencies also reveals a lack of congruence between the statements of the family physicians and paediatrician in some key areas. An important caveat to this part of the discussion is that one pediatrician was interviewed and therefore his experiences and practice reflections may not be representative of all paediatricians in Sault Ste. Marie. Nevertheless, there were some tensions between what the two types of physicians had to say in terms of whether severity of CP was a barrier to transition, and also the balance between broad spectrum and specialist care. For example, the paediatrician implied that family doctors were not comfortable with caring for individuals with more severe forms of CP, but the family doctors stated that they would prefer to be involved and then consult with the paediatricians as needed. This example shows that the physicians in Sault Ste. Marie did not speak with one cohesive voice on some of these important issues.

4.3. Limitations

Methodological limitations exist despite efforts made to ensure sound scientific research. As a partial secondary data analysis, particular areas of concern arise with regards to analysis of OHIP claims data, including several data quality issues such as data completeness, accuracy, and coding. Medical claims to OHIP are considered complete the day following the 6th month of the service date, but changes are continuously implemented and altered after this deadline (Ministry

of Health and Long-Term Care, 2012b). ‘Diagnosis not required/not stated’ is the most commonly cited diagnosis, accounting for 30% of non-laboratory physician services in OHIP, and there is unfortunately no mechanism in place for validating the accuracy of the reason or diagnosis for the patient visit (Ministry of Health and Long-Term Care, 2012b). Other coding issues arise because symptoms rather than actual diagnoses are often recorded, and real diagnoses could be masked (i.e., the symptom of muscle contractures might be used rather than the diagnosis of cerebral palsy). Approximately 25% of claims do not have a diagnosis, and additionally multiple diagnoses can be used interchangeably for the same condition (Ministry of Health and Long-Term Care, 2012b).

In addition to the limitations recognized at the level of OHIP data, it should be noted that there is a population of young adults who may not be represented in this study analysis. Following 18 years of age it has been noted that specialty medical services must be accessed through the adult healthcare system. However, if there is no such specialist available, the use of these medical services will not be represented. For example, during a child’s paediatric years they may be followed by a paediatric neurologist for treatment of epilepsy. However, once they turn 18 years of age, an adult neurologist may not be available for regular follow-up care. In this case, a primary care provider, such as a family physician, would take on the responsibility of monitoring and follow-up of the patient’s epilepsy. While the decrease in service utilization of neurology specialists in the OHIP data may be represented as a change in service needs in the transition age group, it could also be representative of the inability to access this specialized medical service. Further analysis of the OHIP data at the patient level is required to establish which of these possibilities are the most accurate outcome of medical specialist utilization across the lifespan.

Collection of qualitative data through interviews of primary care physicians was mainly limited by the poor study response rate. A total of four physicians were interviewed, including one paediatrician. Although only one paediatrician participated in the study, there are only five paediatricians practicing in Sault Ste. Marie – a 20% response rate for paediatricians. The poor response rate overall is characteristic of this complex adaptive system, as knowledge of the system's history shows a common pattern of poor response rates amongst physician interview participants (Hummers-Pradier et al., 2008). The inability to reimburse physicians monetarily for their time potentially contributed to the limited recruitment.

Additionally, with regards to trustworthiness of the qualitative data, at the time of this thesis approval the analysis of physician interviews was not yet translated back to the physician participants to ensure accuracy of the interview interpretations. The study findings will be sent back to the participating physicians prior to any further publication of the data to ensure trustworthiness of the analysis.

To control these data limitations as much as possible, the OHIP data was requested with the condition that only claims for those patients with a diagnosis of CP were included, which prevented any non-CP patients from being included in the dataset; however, this also means that the dataset is likely under-represented. With regards to interview coding, the possibility of bias due to the researcher's knowledge of current healthcare transition literature was controlled by using an NVivo tool ('word frequency') to outline all of the most frequent topics discussed in the interviews prior to initiation of coding. The interviewer wanted to ensure that coded themes were truly emerging, and not coded based on what has been previously reported in the literature. Rigor was also ensured through the triangulation of the quantitative and qualitative data

validated by the literature, as well as through continued discussion and feedback with a thesis supervisor throughout the study analysis.

The case study methodology used in this thesis limits the generalizability of the findings to healthcare transition models for youth and young adults with CP in different geographies. However, the uniqueness of the study might also be considered innovative. There are no known studies that explore healthcare transition of youth and young adults with CP in an environment where the majority of specialized services used in larger communities are essentially unavailable.

4.4. Implications and Considerations for Future Research and Clinical Change

The findings of this study may serve to help policy makers, future researchers, and healthcare practitioners in understanding the nature of primary healthcare transition with respect to youth and young adults with CP from a perspective of complexity theory. Many researchers and clinicians wonder why there is so little change with regard to primary healthcare and transition of youth and young adults with childhood-onset disorders despite numerous initiatives and process improvement strategies. The answer to these questions may be informed by understanding healthcare organization as a complex adaptive system that is constantly changing and adapting. Methodologically, it is important that further research on this topic maintains a mixed-methods and case study approach, as it is of utmost importance for understanding healthcare transition from a complexity theory perspective.

This research study was designed with a complexity theory perspective, and resulted in numerous recommendations and considerations for future research. Only by exploring the primary physicians' perspectives of healthcare transition in a case study of Sault Ste. Marie did the notion of healthcare transition spreading far beyond that of the physician emerge. It is this study's recommendation that future research consider the inclusion of all care providers who

play a role in the treatment and care of youth and young adults with CP. A pediatrician interviewed in this study made reference to the fact that physicians are a very small piece of the growth and everyday life for youth and young adults living with CP. Using this knowledge, future researchers should expand this study to include a variety of medical specialties, caregivers, therapists, and so on. Participants may include rehabilitative therapists (e.g., occupational therapists, physiotherapists, speech-language pathologists), social workers, community care access centre workers, and respite care workers. Another related focus of future research might be to explore the opinions of advanced practice nurses as future devoted primary care providers for young adults with childhood-onset disorders, an innovative and unique recommendation resulting from this study.

There has been recent discussion in the literature regarding the specialization or focusing of family medicine due to the broadening spectrum and expanding scope of practice. This discussion has led to an initiative by the CFPC to support physicians wishing to focus their practices or run their practices with a special interest (i.e., the SIFP). The interviewees expressed concerns about how the formalization of family practice through the SIFP would impact access to care. The physicians noted that they did not know enough about the program to make an informed opinion. However, they believed that the potential for SIFP in Northern Ontario is very limited, and while the outcomes of SIFP in larger communities may result in beneficial programs or guidelines, in Northern Ontario there is the risk of limiting access to primary care even further. These results further demonstrate the importance of understanding healthcare transition as a whole from a complexity theory perspective.

4.5. Dissemination and Knowledge Translation

It is important that the findings of this study are translated to the academic and medical community, as they provide innovative solutions and a holistic perspective to healthcare transition. Knowledge translation is defined as “a dynamic and iterative process that includes the synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products and strengthen the healthcare system” (Straus, Tetroe & Graham, 2013, p. 4). Networking and connections with the medical community are also very important for knowledge translation of this study’s findings. Prior to the execution of this thesis, networking connections were made with several academic researchers and physicians specializing in primary care of adults with developmental disabilities at the Surrey Place Centre (a medical clinic for adults with developmental disabilities in the Toronto region). Continued contact with these professionals has led to relationships that will assist with the knowledge translation of this study’s findings across the field.

The results of this thesis will be submitted for peer reviewed publication (i.e., Canadian Medical Association Journal, Canadian Family Physician, Family Practice, Developmental Medicine & Child Neurology). Following the thesis defense, a copy of the thesis document and a letter of appreciation will be mailed to the four participating physicians with the request that they share the conclusions of this study with their colleagues. Distribution of the entire thesis document to physicians and other care providers is not necessarily an effective way of disseminating the thesis findings. Therefore, an executive summary as well as the offer to orally present the findings to various physician groups in Sault Ste. Marie (i.e. the ADMG, SFHT) will also occur.

4.6. Conclusion

The appropriate conclusions to be drawn from this study are that in the growing population of adults with CP, those who are likely to be most independent will generally have good health, preserved cognition and few mobility limitations. This population of individuals with less severe forms of CP may not significantly contribute to the challenges of medical transition from paediatric to adult healthcare, due to the mere fact that these individuals have most likely been under the primary care of a family physician their whole lives. However, there are still numerous obstacles to healthcare transition that are challenged by a general lack of services, knowledge, and experience in the adult world. By contrast, poor health, cognitive impairment and relative immobility are factors that are likely to correlate with long-term dependence. It follows that in childhood and during transition to adult life, realistic long-term planning and delivery of comprehensive and appropriate primary healthcare are not only required but should also be, at least potentially, achievable.

The literature shows that the adult healthcare system is ill equipped to deal with the growing population of adults with childhood-onset disorders (Young, 2007). Therefore, by studying Sault Ste. Marie as an example, this study has provided insight into the primary healthcare of youth and young adults with CP in an environment that functions with limited resources on a regular basis. Analysis of OHIP billing claims for physician services provided to youth and young adults with CP in Sault Ste. Marie provided evidence of service utilization changes across the transitioning years. Using the current literature on healthcare transition as well as insight from primary care physicians in Sault Ste. Marie, this study was able to show that the changes in medical specialist service utilization following the age of transition is due to both the expiration of paediatric services, as well as the changing health needs of young adults with CP as they age.

The changing patterns of service use for youth and young adults with CP in Sault Ste. Marie are fundamental in understanding the themes that emerged from the interview analysis and together in understanding the complexity of healthcare transition.

Physician interviews provided evidence of the complexity associated with healthcare transition of youth and young adults with CP, which is compounded further by various factors such as severity of disability, the lack of knowledge and experience of adult providers in caring for people with CP, a lack of coordination and a disconnect between providers and available services and resources.

It is essential to acknowledge that transition processes developed in a very specific manner for such a complex and variable population has a high potential for failure. Complexity theory teaches us that in a complex adaptive system, the application of relatively simple rules can lead to emergent and innovative system behaviour (Plsek, 2001). There have been several attempts to set out a complex set of rules (e.g., guidelines, position statements) to govern healthcare transition. When these have not yielded desired results, the response has been to create even more rules, policies, and guidelines with the ultimate goal of creating a ‘fix’. Complexity science stresses that these types of action take us in exactly the wrong direction. The answer is to create the conditions for self-organization and through simple rules under which the system will adapt and evolve (Plsek, 2001).

Due to the adaptable and evolving nature of complex systems, the current goal with respect to health care transition processes for youth and young adults with childhood-onset disabilities is to generate a ‘good enough plan’ (Plsek, 2001) and begin to observe what happens. Then, modifications can occur in an evolutionary fashion. It may take an entire generation of physicians to obtain an adult healthcare system that is comfortable, experienced and well-trained

in caring for adults with CP across the spectrum of severities. The findings of this study suggest that until the system evolves and adapts to the growing population of adults with CP, there should be simple processes in place to assist them in obtaining access to the services and resources they need. It is a fact that healthcare is a complex adaptive system, which ensures that it will adapt and evolve over time to support the needs of the system's agents (i.e., physicians and adults with CP). Until that time, it is essential that a 'good enough plan' be established to ensure that the current population of youth and young adults transitioning to the adult health-care system does not slip through the cracks with respect to primary healthcare services.

This thesis study has provided multiple perspectives and opinions of primary care providers from a community that survives on a regular basis with limited specialized medical care and clinical resources. From the qualitative analysis, the emerging topic surrounding coordination of care with the proposed solution of utilizing nurse practitioners as primary care providers and overall coordinators for transitioning youth and young adults was very interesting. It was surprising that only one physician mentioned this model as an option with the growing literature and endorsement of nurse practitioner clinics in Ontario (Ministry of Health and Long-Term Care, 2012a). In future research, it may be of great benefit to test the efficacy of nurse practitioners as primary care providers and coordinators of care for young adults with childhood-onset disabilities.

The findings of this thesis may help to acknowledge the complexity associated with healthcare transition and the future direction of primary care for youth and young adults with CP. It is hoped that future research in healthcare transition for youth and young adults with childhood-onset disabilities, such as CP, will be informed by complexity science such that the system can be interpreted as an integral whole. It is only by understanding the complex nature of

CP and healthcare transition that we can move forward in providing comprehensive and quality primary healthcare for individuals living with CP across the lifespan.

References

- Aisen, M. L., Kerkovich, D., Mast, J., Mulroy, S., Wren, Tishya A. L., Kay, Robert M., & Rethlefsen, Susan A. (2011). Cerebral palsy: clinical care and neurological rehabilitation. *The Lancet Neurology*, 10(9), 844-852.
- Alberta Health Services. (2008). Be Your Own Boss Program. Retrieved March 2013, from <http://www.albertahealthservices.ca/services.asp?pid=service&rid=1031355>
- Allen, P. J., Vessey, J. A., & Shapiro, N. A. (2010). *Primary care of the child with a chronic condition, Fifth Edition*. S. Louis, MI: Mosby Inc, Elsevier.
- American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, & Transitions Clinical Report Authoring Group. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 128(1), 182-200. doi: 10.1542/peds.2011-0969
- American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine. (2002). A consensus statement on health care transition for young adults with special health care needs. *Pediatrics*, 110(6, pt 2), 1304-1306.
- Anderson, R, Crabtree, BF, Steele, DJ, & McDaniel, RR. (2005). Case study research: the view from complexity science. *Qualitative Health Research*, 15(5), 669-685.
- Arneson, C. L., Durkin, M. L., Benedict, R. E., Kirby, R. S., Yeargin-Allsopp, M., Van Naarden Braun, K., & Doernberg, N. S. (2009). Prevalence of cerebral palsy: Autism and Developmental Disabilities Monitoring Network, three sites, United States, 2004. *Disabil Health J*, 2(1), 45-48.

- Baawaating Family Health Team. (2013). Baawaating Family Health Team. from <https://sites.google.com/site/baawaatingfht/home>
- Bailey, T. (2007). Filling the gaps: a divergent community of family physicians. *Canadian Family Physician*, 53, 1393.
- Beaulieu, M. D., Rioux, M., Rocher, G., Samson, L., & Boucher, L. (2008). Family practice: professional identity in transition. A case study of family medicine in Canada. *Soc Sci Med*, 67(7), 1153-1163. doi: 10.1016/j.socscimed.2008.06.019
- Binks, J. A., Barden, W. S., Burke, T. A., & Young, N. L. (2007). What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Arch Phys Med Rehabil*, 88(8), 1064-1073.
- Blair, E. (2010). Epidemiology of the cerebral palsies. *Orthopedic Clinics of North America*, 41(4), 441-455. doi: 10.1016/j.ocl.2010.06.004
- Blum, R. W., Garell, D., Hodgman, C. H., Jorissen, T. W., Okinow, N. .A, Orr, D. P., & Slap, G. B. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: A position paper for the society of adolescent medicine. *Journal of Adolescent Health*, 14, 570-576.
- Bodenheimer, T. (2007). Coordinating care: A perlious journey through the health care system. *New England Journal of Medicine*, 358(10), 1064-1084.
- Bottos, M., Feliciangeli, A., Sciuto, I., Gericke, C., & Vianello, A. (2001). Functional status of adults with cerebral palsy and implications for treatment of children. *Developmental Medicine & Child Neurology*, 43(516-528).

- Burke, R., Spoerri, M., Price, A., Cardosi, A. M., & Flanagan, P. (2008). Survey of primary care pediatricians on the transition and transfer of adolescents to adult health care. *Clin Pediatr (Phila)*, 47(4), 347-354. doi: 10.1177/0009922807310938
- Canadian Paediatric Society. (2007). Transition to adult care for youth with special health care needs. *Paediatric Child Health*, 12(9), 785-788.
- Cans, C. (2000). Surveillance of cerebral palsy in Europe: A collaboration of cerebral palsy surveys and registers. *Developmental Medicine & Child Neurology*, 42, 816-824.
- College of Family Physicians of Canada. (2008). Family physicians with special interests or focused practices. Retrieved September 2012, from <http://www.cfpc.ca/SIFP/>
- College of Family Physicians of Canada, Canadian Medical Association, & Royal College of Physicians and Surgeons of Canada. (2007). National Physician Survey, 2007. Retrieved March 2013, from <http://nationalphysiciansurvey.ca/surveys/2007-survey/>
- College of Physicians and Surgeons of Ontario. (2013). Doctor Search. Retrieved March 2013, from <http://www.cpsso.on.ca/publicregister/default.aspx?id=2048>
- Collier, R. (2011, November 1). The changing face of family medicine, *Canadian Medical Association Journal News*.
- Cooley, W. C., & American Academy of Pediatrics Committee on Children With Disabilities. (2004). Providing a primary care medical home for children and youth with cerebral palsy. *Pediatrics*, 114(4), 1106-1113.
- Cooley, W. C., & Sagerman, P. J. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 128(1), 182-200.
- Creswell, J. W. (2012). *Qualitative inquiry and research design, third edition*. Washington, DC: SAGE Publications.

Day, S. M., Stauss, D. J., Vachon, P. J., Rosenbloom, L., Shavelle, R. M., & Wu, Y. M. (2007).

Growth patterns in a population of children and adolescents with cerebral palsy.

Developmental Medicine & Child Neurology, 49, 167-171.

Disability Services Commission. (2012). Shared Management Model. Retrieved March 2013,

from

http://www.disability.wa.gov.au/reform1/reform/sector_development/shared_management/-Related_publications

Fierlbeck, K. (2011). *Health care in Canada: a citizen's guide to policy and politics*. Toronto:

University of Toronto Press.

Forsgren, L. (1996). Epidemiology: incidence and prevalence. In S. Wallace (Ed.), *Epilepsy in*

Children (pp. 27-37). London: Chapman and Hall.

Fox, A. (2002). Physicians as barriers to successful transitional care. *International Journal of*

Adolescent Medicine and Health, 14, 3-7.

Gall, C., Kingsnorth, S., & Healy, H. (2006). Growing up ready: a shared management approach.

Physical & Occupational Therapy In Pediatrics, 26(4), 47-62. doi:

10.1300/J006v26n04_04

Gibson, B. E., Teachman, G., Wright, V., Fehlings, D., Young, N. L., & McKeever, P. (2012).

Children's and parent's beliefs regarding the value of walking: rehabilitative implications for children with cerebral palsy. *Child: Care, Health & Development*, 38(1), 61-69.

Glouberman, S., & Zimmerman, B. (2002). Complicated and complex systems: what would

successful reform of medicare look like? *In Discussion paper No. 8: Commission on the Future of Health Care in Canada*. Ottawa.

- Good2Go Transition Program. (2009). Good2Go Transition Program. Retrieved March 2013, from <http://www.sickkids.ca/Good2Go/index.html>
- Gorter, J. W., Stewart, D., & Woodbury-Smith, M. (2011). Youth in transition: care, health and development. *Child: Care, Health & Development*, 37(6), 757-763. doi: 10.1111/j.1365-2214.2011.01336.x
- Gramtham-McGregor, S. M., Powell, C. A., Walker, S. P., & Himes, J. H. (1991). Nutritional supplementation, psychosocial stimulation, and mental development of stunted children: the Jamaican study. *Lancet*, 388, 126-138.
- Grant, C., & Pan, J. (2011). A comparison of five transition programmes for youth with chronic illness in Canada. *Child: Care, Health & Development*, 37(6), 815-820. doi: 10.1111/j.1365-2214.2011.01322.x
- Green, L. A., & Fryer, G. E. (2002). Family practice in the United States: position and prospects. *Academic Medicine*, 77, 781-789.
- Green, M. (1994). *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*. VA: National Maternal and Child Health Clearinghouse,.
- Group Health Centre. (2013a). Algoma District Medical Group (ADMG): our team. Retrieved March 2013, from <http://www.ghc.on.ca/admg/doctors.html>
- Group Health Centre. (2013b). Group Health Centre: About GHC. Retrieved March 15, 2013, from <http://www.ghc.on.ca/about/content.html?sID=2>
- Guelber, A. (2008). Life's transitions: Calgary's YARD clinic helps patients navigate the medical system. *Canadian Rheumatology Association Journal*, 18, 16-17.
- Gutkin, C. (2008). Combining our skills to strengthen our future: family physicians with special-interest and focused practice. *Canadian Family Physician*, 54, 1200.

- Haak, P., Lenski, M., Hidecker, M. J., Li, M., & Paneth, N. (2009). Cerebral palsy and aging. *Developmental Medicine & Child Neurology*, 51 Suppl 4, 16-23.
- Hadjipanayis, A., Hadjichristodoulou, C., & Youroukos, S. (1997). Epilepsy in patients with cerebral palsy. *Developmental Medicine & Child Neurology*, 39, 659-663.
- Haggerty, J., Burge, F., Levesque, J., Gass, D., Pineault, R., beaulieu, M., & Santor, D. (2007). Operational definitions of attributes of primary health care: Consensus among Canadian experts. *Annals of Family Medicine*, 5, 336-344.
- Hamdani, Y., Jetha, A., & Norman, C. (2011). Systems thinking perspectives applied to healthcare transition for youth with disabilities: a paradigm shift for practice, policy and research. *Child: Care, Health & Development*, 37(6), 806-814.
- Hanna, S. E., Rosenbaum, P., Bartlett, D., Palisano, R., Walter, S., Avery, L., & Russel, D. (2009). Stability and decline in gross motor function among children and youth with cerebral palsy aged 2 to 21 years. *Developmental Medicine & Child Neurology*, 51(4), 295-302.
- Health Council of Canada. (2009). Getting it right: Case studies of effective management of chronic disease using primary health care teams. Toronto: Health Council.
- Health Force Ontario. (2013). Training and practicing in Ontario: Locum. Retrieved July 21, 2013, from http://www.healthforceontario.ca/en/Home/Physicians/Training_%7C_Practising_in_Ontario/Locum
- Hemming, K., Hutton, J. L., & Pharoah, P. O. (2006). Long-term survival for a cohort of adults with cerebral palsy. *Developmental Medicine & Child Neurology*, 48(2), 90-95.

- Hilberink, S. R., Roebroek, M. E., Nieuwstraten, W., Jalink, L., Verheijden, J. M. A., & Stam, H. J. (2007). Health issues in young adults with cerebral palsy: towards a life-span perspective. *Journal of Rehabilitation Medicine*, 39, 605-611.
- Hogg, W., Rowan, M., Russell, G., Geneau, R., & Muldoon, L. (2008). Framework for primary care organizations: The importance of a structural domain. *International Journal for Quality in Health Care*, 20, 308-313.
- Hummers-Pradier, E., Scheidt-Nave, C., Martin, H., Heinemann, S., Kochen, M., & Himmel, W. (2008). Simply no time? Barriers to GPs' participation in primary health care research. *Family Practice*, 25(2), 105-112.
- Iams, J.D., Romero, R., Culhane, J.F., & Goldenberg, R.L. (2008). Preterm birth 2 - Primary, secondary, and tertiary interventions to reduce the morbidity and mortality of preterm birth. *Lancet*, 371(9607), 164-175.
- Institute of Medicine. (1994). Defining primary care: An interim report. M. Donadson, K. Yordy, and N. Vanselow (Eds.) Washington, DC: National Academy Press.
- Jeglinsky, I., Autti-Ramo, I., & Brogren Carlberg, E. (2012). Professional background and the comprehension of family-centredness of rehabilitation for children with cerebral palsy. *Child: Care, Health & Development*, 38(1), 70-78.
- Jones, M. W., Morgan, E., & Shelton, J. E. (2007). Primary care of the child with cerebral palsy: a review of systems (part II). *Journal of Pediatric Health Care*, 21(4), 226-237.
- Katz, R. (2003). Life expectancy for children with cerebral palsy and mental retardation: implications for life care planning. *NeuroRehabilitation*, 18, 261-270.

- Kennedy, A., Sloman, F., Douglass, J. A., & Sawyer, S. M. (2007). Young people with chronic illness: the approach to transition. *Intern Med J*, 37(8), 555-560. doi: 10.1111/j.1445-5994.2007.01440.x
- Kieckhefer, G. M., & Trahms, C. M. (2000). Supporting development of children with chronic conditions: From compliance toward shared management. *Pediatric Nursing*, 26(4), 354-363.
- King, G. A., Baldwin, P. J., Currie, M., & Evans, J. (2006). The effectiveness of transition strategies for youth with disabilities. *Children's Health Care*, 35(2), 155-178.
- Kirby, R. S., Wingate, M. S., Van Naarden Braun, K, Doernberg, N. S., Arneson, C. L., Benedict, R. E., . . . Yeargin-Allsopp, M. (2011). Prevalence and functioning of children with cerebral palsy in four areas of the United States in 2006: a report from the Autism and Developmental Disabilities Monitoring Network. *Research in Developmental Disabilities*, 32(2), 462-469.
- Krick, J., & Van Duyn, M. A. (1984). The relationship between oral-motor involvement and growth: a pilot study in a pediatric population with cerebral palsy. *Journal of the American Dietetic Association*, 84, 555-559.
- Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The Person-Environment-Occupational Model: a transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63(1), 9-23.
- Lovell, R. W., & Reiss, A. L. (1993). Dual diagnoses. Psychiatric disorders in developmental disabilities. *Pediatric Clinics of North America*, 40(3), 579-592.
- Martin, C. M. & Sturmberg, J. P. (2009). Perturbing conversations about systems and complexity science. *Journal of Evaluation in Clinical Practice*, 15, 549-552.

- McDonagh, J. E. (2005). Growing up and moving on: transition from pediatric to adult care. *Pediatr Transplant*, 9, 364-372.
- McDonagh, J. E., & Kelly, D. A. (2010). The challenges and opportunities for transitional care research. *Pediatr Transplant*, 14(6), 688-700.
- McManus, M., Fox, H., O'Connor, K., Chapman, T., & MacKinnon, J. (2008). Pediatric perspectives and practices on transitioning adolescents with special needs to adult health care *Health Care Transition*. Washington, DC: The National Alliance to Advance Adolescent Health.
- Mill, A., Mayes, R., & McConnell, D. (2010). Negotiating autonomy within the family: the experiences of young adults with intellectual disabilities. *British Journal of Learning Disabilities*, 38, 194-200.
- Ministry of Health and Long-Term Care. (2007). Preventing and managing chronic disease: Ontario's Framework.
- Ministry of Health and Long-Term Care. (2012a). Family Health Teams. Retrieved March 6, 2013, from <http://www.health.gov.on.ca/en/pro/programs/fht/>
- Ministry of Health and Long-Term Care. (2012b). Health analysis toolkit. Toronto: MOHLTC - Health Analytics Branch.
- Ministry of Health and Long-Term Care. (2013). *Schedule of Benefits for Physician Services under the Health Insurance Act*. Government of Ontario.
- Muldoon, L., Rowan, M. S., Geneau, R., Hogg, W., & Coulson, D. (2006). Models of primary care delivery in Ontario: why such diversity? *Healthcare Management Forum*, 19(4), 18-23.

- Murphy, K. P., Molnar, G. E., & Lankasky, K. (1995). Medical and functional status of adults with cerebral palsy. *Developmental Medicine & Child Neurology*, 37(1075-1084).
- Murphy, N. A., Hoff, C., Jorgensen, T., Norlin, C., & Young, P. C. (2006). Costs and complications of hospitalizations for children with cerebral palsy. *Pediatric Rehabilitation*, 9, 47-52.
- National Center for Cultural Competence. (2007). A guide for advancing family-centred and culturally and linguistically competent care: Georgetown University Centre for Child and Human Development.
- O'Shea, T. M. (2008). Diagnosis, treatment, and prevention of cerebral palsy in near-term/term infants. *Clinical Obstetrics and Gynecology*, 51(4), 816-828.
- Okumura, M. J., Kerr, E. A., Cabana, M. D., Davis, M. M., Demonner, S., & Heisler, M. (2010). Physician views on barriers to primary care for young adults with childhood-onset chronic disease. *Pediatrics*, 125(4), e748-754.
- Organization for Economic Co-operation and Development. (2007). OECD Health Data 2007: Comparative analysis of 30 countries: OECD Publishing.
- Oskoui, M. (2012). Growing up with cerebral palsy: contemporary challenges of healthcare transition. *The Canadian Journal of Neurological Sciences*, 39, 23-25.
- Palisano, R., Rosenbaum, P., Walter, S., Russel, D., Wood, E., & Galuppi, B. (1997). Gross Motor Function Classification System for Cerebral Palsy. *Developmental Medicine & Child Neurology*, 39, 214-223.
- Paneth, N., Hong, T., & Korzeniewski, S. (2006). The descriptive epidemiology of cerebral palsy. *Clinical Perinatology*, 33(2), 251-267.

- Paone, M. (2001). *Setting the Trac: A resource for health care professionals supporting youth with chronic conditions and their families*. Vancouver, BC: Children's and Women's Health Centre of BC.
- Patel, M. S., & O'Hare, K. (2010). Residency training in transition of youth with childhood-onset chronic disease. *Pediatrics*, *126 Suppl 3*, S190-193.
- Peter, N. G., Forke, C. M., Ginsburg, K. R., & Schwarz, D. F. (2009). Transition from pediatric to adult care: internists' perspectives. *Pediatrics*, *123*(2), 417-423.
- Plsek, P. E. (2001). Appendix B-redesigning health care with insights from the science of complex adaptive systems. *Crossing the quality chasm: a new health system for the 21st century* (pp. 309-322). Washington, D.C: National Academy of Science.
- Plsek, P. E., & Greenhalgh, T. (2001). Complexity science: the challenge of complexity in health care. *British Medical Journal*, *323*(7313), 625-628.
- Pong, R. W. (2008). Strategies to overcome physician shortages in northern Ontario: a study of policy implementation over 35 years. *Hum Resour Health*, *6*(24), 1-9. doi: 10.1186/1478-4491-6-24
- Provincial Council for Maternal and Child Health, Child and Youth Advisory Committee, & Transition to Adult Healthcare Services Work Group. (2011). Report of the transition to adult healthcare services work group.
- QSR International. (2012). NVivo 10 from http://www.qsrinternational.com/products_nvivo.aspx
- Reilly, S., Skuse, D., & Pople, X. (1996). Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: a community survey. *J Pediatr*, *129*(6), 877-882.

- Reiss, J. (2012). Health care transition for emerging adults with chronic health conditions and disabilities. *Pediatric Annals*, 41(10), 429-435.
- Reiss, J., & Gibson, R. (2002). Health care transition: Destinations unknown. *Pediatrics*, 110, 1307-1313.
- Reiss, J., Gibson, RW, & Walker, LR. (2005). Health care transition: youth, family, and provider perspectives. *Pediatrics*, 115(1), 112-120. doi: 10.1542/peds.2004-1321
- Rempel, G. R., Colwell, S. O., & Nelson, R. P. (1988). Growth in children with cerebral palsy fed via gastrostomy. *Pediatrics*, 82, 857-862.
- Rosen, D. (1995). Between two worlds: bridging the cultures of child health and adult medicine. *Journal of Adolescent Health*, 17, 10-16.
- Rosenbaum, P. (2003). Cerebral palsy: what parents and doctors want to know. *British Medical Journal*, 326, 970-974.
- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., & Bax, M. (2007). A report: the definition and classification of cerebral palsy, April 2006. *Developmental Medicine & Child Neurology*, 49(8-14).
- Rosenbaum, P., & Rosenbloom, L. (2012). *Cerebral palsy: from diagnosis to adult life*. London, ON: Mac Keith Press.
- Rosenthal, T. C. (2008). The medical home: growing evidence to support a new approach to primary care. *The Journal of the American Board of Family Medicine*, 21(5), 427-440.
- Rosser, W. (2002). The decline of family medicine as a career choice. *Canadian Medical Association Journal*, 166, 1419-1420.
- Rosser, W., Colwill, J. M., Kasperski, J., & Wilson, L. (2010). Patient-centred medical homes in Ontario. *New England Journal of Medicine*, 362(e7), 1-3.

- Rosser, W., Colwill, J. M., Kasperski, J., & Wilson, L. (2011). Progress of Ontario's Family Health Team model: a patient-centered medical home. *Ann Fam Med*, 9(2), 165-171.
- Rosser, W., & Kaperski, J. (1999). Organizing primary care for an integrated system. *Healthcare Papers*, 1(1), 5-21.
- Russel, D., Rosenbaum, P., Cadman, D. T., Gowland, C., Hardy, S., & Jarvis, S. (1989). The gross motor function measure: a means to evaluate the effects of physical therapy. *Developmental Medicine & Child Neurology*, 31(3), 341-352.
- Salmon, P., Peters, S., Rogers, A., Gask, L., Clifford, R., Iredale, W., . . . Morriss, R. (2007). Peering through the barriers in GPs' explanations for declining to participate in research: the role of professional autonomy and the economy of time. *Family Practice*, 24(3), 269-275.
- Sanders, K. D. , Cox, K., Cannon, R., Blanchard, D., Pitcher, J., Papathakis, P., . . . Maughan, R. (1990). Growth response to enteral feeding by children with cerebral palsy. *Journal of Parenteral and Enteral Nutrition*, 14, 23-26.
- SaultMed. (2012). Partners in health care. Retrieved March 2013, from http://www.saultmed.com/SaultMed_Partners_in_Health_Care.aspx
- Scal, P. (2002). Transition for youth with chronic conditions: primary care physicians' approaches. *Pediatrics*, 110(Supplement 3), 1315-1321.
- Schultz, A. W., & Liptak, G. S. (1998). Helping adolescents who have disabilities negotiate transitions to adulthood. *Issues in Comprehensive Pediatric Nursing*, 21(5), 187-201.
- Sherman, S. E. (2008). A framework for tobacco control: lessons learnt from veterans health administration. *British Medical Journal*, 336(7651), 1016-1019.

- Simoens, S., & Hurst, J. (2006). The supply of physician services in OECD countries *OECD Health Working Papers* (Vol. 21).
- Stallings, V. A., Charney, E. B., Davies, J. C., & Cronk, C. E. (1993). Nutrition-related growth failure of children with quadriplegic cerebral palsy. *Developmental Medicine & Child Neurology*, 35, 126-135.
- Statistics Canada. (2011). Sault Ste. Marie, Ontario (Code 3557061) and Algoma, Ontario (Code 3557) (table). Census Profile. 2011 Census. Statistics Catalogue no. 98-316-XWE. Retrieved May 11, 2013, from <http://www12.statcan.gc.ca/census-recensement/2011/dp-pd/prof/index.cfm?Lang=E>
- Stewart, D. A. (2009). Transition to adult services for young people with disabilities: current evidence to guide future research. *Developmental Medicine & Child Neurology*, 51 Suppl 4, 169-173.
- Stewart, D. A., Law, M., Rosenbaum, P., & Willms, D. (2001). A qualitative study of the transition to adulthood for youth with physical disabilities. *Physical & Occupational Therapy In Pediatrics*, 21(4), 3-21.
- Stewart, D. A., Stavness, C., King, G., Antle, B., & Law, M. (2006). A critical appraisal of literature reviews about the transition to adulthood for youth with disabilities. *Physical & Occupational Therapy In Pediatrics*, 26(4), 5-24. doi: 10.1300/J006v26n04_02
- Stoch, M. B., Smyth, P. M., Moodie, A. D., & Bradshaw, D. (1982). Psychosocial outcome and CT findings after gross undernourishment during infancy: a 20-year developmental study. *Developmental Medicine & Child Neurology*, 24, 419-436.

- Strong, S., Rigby, P., Stewart, D., Law, M., Letts, L., & Cooper, B. (1999). Application of the Person-Environment-Occupational Model: A practical tool. *Canadian Journal of Occupational Therapy*, 66(3), 122-133.
- Sullivan, P. (2009). *Feeding and nutrition in children with neurodevelopmental disability*. London, ON: Mac Keith Press.
- Sullivan, P., Lambert, B., Rose, M., Ford-Adams, M., & Johnson, A. (2000). Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford feeding study. *Developmental Medicine & Child Neurology*, 42(10), 674-680.
- Sullivan, W. F., Berg, J. M., Bradley, E., Cheetham, T., Denton, R., Heng, J., . . . McMillan, S. (2011). Primary care of adults with developmental disabilities: Canadian consensus guidelines. *Canadian Family Physician*, 57, 541-553.
- Superior Family Health Team. (2012). Superior Family Health Team. Retrieved March 2013, from <http://www.superiorfht.ca/>
- Templeton, L., Deehan, A., Taylor, C., Drummond, C., & Strang, J. (1997). Surveying general practitioners: does a low response rate matter? *British Journal of General Practice*, 47(415), 91-94.
- The Royal College of Physicians of Edinburgh Steering Group. (2008). Think transition: developing the essential link between paediatric and adult care. Edinburgh, Scotland.
- US Department of Health and Human Services, Health Resources and Service Administration, & Maternal and Child Health Bureau. (2004). The national survey of children with special health care needs chartbook, 2001. Rockville, Maryland.

- Van Wallegghem, N. (2006). Building connections for young adults with type 1 diabetes mellitus in Manitoba: feasibility and acceptability of transition initiative. *Chronic Diseases Canada, 27*, 130-134.
- Viner, R. M. (1999). Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child, 81*, 271-275.
- Viner, R. M. (2008). Transition of care from paediatric to adult services: one part of improved health services for adolescents. *Arch Dis Child, 93*(2), 160-163.
- Waterman, E. T., Koltai, P. J., Downey, J. C., & Cacace, A. T. (1992). Swallowing disorders in a population of children with cerebral palsy. *International Journal of Pediatric Otorhinolaryngology, 24*, 63-71.
- Wenghofer, E. F., Timony, P. E., & Pong, R. W. (2011). A closer look at Ontario's northern and southern physician demographics. *Rural and Remote Health, 11*, 1591-1602.
- White, J., & Bero, L. A. (2004). Public health under attack: the American Stop Smoking Intervention Study (ASSIST) and the tobacco industry. *American Journal of Public Health, 94*(2), 240-250.
- Wilson, T., & Holt, T. (2001). Complexity science: Complexity and clinical care. *British Medical Journal, 323*(7314), 685-688.
- Young, N. L. (2007). The transition to adulthood for children with cerebral palsy: What do we know about their health care needs? *Journal of Pediatric Orthopedics, 27*(4), 476-479.
- Young, N. L., McCormick, A. M., Gilbert, T., Ayling-Campos, A., Burke, T., Fehlings, D., & Wedge, J. (2011). Reasons for hospital admissions among youth and young adults with cerebral palsy. *Archives of Physical and Medical Rehabilitation, 92*(1), 46-50. doi: 10.1016/j.apmr.2010.10.002

Appendices

Appendix A: Ethics Certification - Laurentian University Research Ethics Board



APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New X /	Modifications to project / Time extension
Name of Principal Investigator and school/department	Chelsea Seguin
Title of Project	Understanding the Primary Health Care Transition of Youth with Cerebral Palsy from the Perspectives of Pediatricians and Family Physicians in a Northern Ontario Community
REB file number	2012-07-09
Date of original approval of project	July 24, 2012
Date of approval of project modifications or extension (if applicable)	
Final/Interim report due on	July 24, 2013
Conditions placed on project	<p>Please change the following sentence on the consent:</p> <p>I understand that I may contact the acting chair of the Laurentian Research Ethics Board regarding possible ethical issues or complaints about the research itself. Dr. Susan James may be reached at sjames@laurentian.ca.</p> <p>To: I understand that I may contact the Laurentian University Ethics office regarding possible ethical issues or complaints about the research itself. The ethics officer may be reached at ethics@laurentian.ca</p> <p>Final report due on July 23, 2013</p>

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate [REB form](#).

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate [REB form](#).

In all cases, please ensure that your research complies with [Tri-Council Policy Statement \(TCPS\)](#). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best of luck in conducting your research.

Susan James, Acting chair
Laurentian University Research Ethics Board

Appendix B: Ethics Certification - Joint Group Health Centre/Sault Area Hospital



GROUP HEALTH CENTRE



SAULT AREA
HOSPITAL
HÔPITAL DE
SAULT-SAINTE-MARIE

November 26, 2012

Ms. Chelsea Seguin
Masters Student in Interdisciplinary Human Development
Laurentian University
935 Ramsey Lake Road
Sudbury, Ontario
P3E 2C6

Dear Ms. Seguin;

The Chairperson of the Joint Group Health Centre/Sault Area Hospital Research Ethics Board received application for expedited review of the *Abstract, Consent to Participate, Interview Script Questions, Research Study Participation Reminder Card, Dear Physician Letter and Supplementary Consent for Use of Collected Interview Data*, of the protocol **Understanding the Primary Health care Transition of Youth with Cerebral Palsy from the Perspectives of Pediatricians and Family Physicians in a Northern Ontario Community.**

Expedited approval of the *Abstract, Consent to Participate, Interview Script Questions, Research Study Participation Reminder Card, Dear Physician Letter and Supplementary Consent for Use of Collected Interview Data* has been granted. Notification of the revision will be an agenda item at the next regularly scheduled Research Ethics Board meeting.

No changes, amendments or addenda may be made in the protocol or the consent form without the Research Ethics Board review and approval.

The Joint Group Health Centre/Sault Area Hospital Research Ethics Board is constituted and functions in accordance with the ICH GCP and the Tri-Council Policy Statement guidelines.

Yours sincerely,

Jane Sippell
Co-Chairperson
Joint Group Health Centre/Sault Area Hospital
Research Ethics Board

JS:ag

Appendix C: Ministry of Health and Long Term Care: Data Application Form - Data Element Request

Seguin, Chelsea

DATA APPLICATION FORM – Data Element Request

Two-Step Data Request: Elements for each step

Step 1: OHIP Fee-for-Service Claims History Data – Between March 31st, 2002 and April 1st, 2012

DATA ELEMENTS	RATIONALE	NOTES
All Assessment (A Codes) and Consultation (C Codes) claims within the Northeast and Northwest LIHNs with a diagnostic code of Cerebral Palsy (Code: 343)	To capture as many patients as possible that have had at least one diagnostic claim of Cerebral Palsy	The claims generated from this data search will be used in the second step of data request (see below, Step 2)

Step 2: OHIP Fee-for-Service Claims History Data – Between March 31st, 2006 and April 1st, 2012

For this second step, I would like to request the following data elements from all of the patients identified in Step 1. Since OHIP claims are made for individual services not individual patients, the list of claims generated from Step 1 may include duplicate patients. If possible, I would like to request that the MOHLTC analyst eliminate any duplicate patients from within this list. This extra step would prevent having to request for patient identifiers for manual removal of duplicate patients. From the final list of claims with a diagnostic code of CP attached, please provide the all outpatient assessment and consult claims (A and C codes) with the following attached data elements:

DATA ELEMENTS	RATIONALE	NOTES
Patient: Sex Age in years Location (LIHN & 1 st three digits of postal code if possible)	For demographic differences in descriptive analysis. To identify changes in primary care service access over time.	These three sets of data elements are only for the list of patients identified in Step 1 of the data request.
Provider: Sex Age Location (LIHN & 1 st three digits of postal code if possible)	For demographic differences in descriptive analysis. To identify changes in provider services over time.	
Service: Specialty Code MOHLTC diagnosis code Service Date	To identify changes in provider specialty/multiple providers. To identify changes in "diagnostic" code over time. To identify frequency of service access.	

Appendix D: Sensitivity Analysis

Prevalence Rate	Age Groups			
	0-16	17-21	0-17	18-21
National				
Prevalence	367 claims per	174 claims per	384 claims per	138 claims per
(3.3 per 1000)	1000	1000	1000	1000
NE LHIN				
Prevalence	245 claims per	116 claims per	256 claims per	92 claims per
(2.2 per 1000)	1000	1000	1000	1000

Northeast LHIN (NE LHIN) prevalence rate of CP in 0-21 year olds is calculated as 2.2 per 1000 individuals. Calculation used population of NE LHIN by age group (North East LHIN, 2008) and volume of residents 0-21 with CP in the NE LHIN (verified and supplied through request to the NE LHIN, queried through the Medical Services Database in IntelliHEALTH ONTARIO).

Appendix E: Dear Doctor Letter



August 23, 2012

Dear Dr. (insert physician name),

I am writing today to inform you of a research study titled:
Understanding the Primary Health Care Transition of Youth with Cerebral Palsy from the Perspectives of Pediatricians and Family Physicians in a Northern Ontario Community,
that I am conducting for my Master's Thesis.

The purpose of this study is to receive feedback from physicians on the topic of primary health care transition of youth and young adults with cerebral palsy from the pediatric health care system to adult-oriented primary care. Additionally, this study will explore physician experiences of transition barriers, as well as brainstorm possible innovative solutions for transition in Northern Ontario.

As a primary care physician in Sault Ste. Marie, Ontario, you are eligible to participate in a one-on-one interview with myself to provide your opinions and discuss the topics outlined above. Your participation in this study is voluntary and you have the right to withdraw at any time without penalty. A copy of an Informed Consent Form has been included for your review.

If you would like to participate in this study, please contact me at the email address provided and we can set up a date, time and location for an interview at your earliest convenience. If you have not responded within four weeks of receiving this letter, I will mail out a reminder card.


Thank you in advance for your time,

Chelsea Seguin

cseguin2@laurentian.ca

Master's Candidate, Interdisciplinary Human Development
Laurentian University
Sudbury, ON

Appendix F: Reminder Cards

	
RESEARCH STUDY PARTICIPATION	
Understanding the Primary Health Care Transition of Youth with Cerebral Palsy from the Perspectives of Pediatricians and Family Physicians in a Northern Ontario Community	
REMINDER!	
Chelsea Seguin Email: cseguin2@laurentian.ca Master's Candidate, Interdisciplinary Human Development Laurentian University Sudbury, ON	Recipient
[INSERT DATE] REMINDER! You are invited to participate in a Master's Thesis study.	Address Line 1 Address Line 2 Address Line 3 Address Line 4
<p>The purpose of this study is to receive feedback from physicians on the topic of primary health care transition of youth and young adults with cerebral palsy from the pediatric health care system to adult-oriented primary care. Additionally, this study will explore physician experiences of transition barriers, as well as brainstorm possible innovative solutions for transition in Northern Ontario.</p> <p>As a primary care physician in Sault Ste. Marie, Ontario, you are eligible to participate in a one-on-one interview with myself to provide your opinions and discuss the topics outlined above. Your participation in this study is voluntary</p> <p>If you would like to participate in this study, please contact me at the email address provided and we can set up a date, time and location for an interview at your earliest convenience.</p>	

Appendix G: Informed Consent Forms (Main and Supplementary)



Consent to Participate

Interview Discussion of Master's Thesis for Primary Care Physicians entitled

"Understanding the Primary Health Care Transition of Youth with Cerebral Palsy from the Perspectives of Pediatricians and Family Physicians in a Northern Ontario Community"

- Purpose:** To receive feedback on the topic of primary health care transition of youth and young adults with cerebral palsy from the pediatric health care system to adult primary care. Additionally, identify physician experiences of transition barriers as well as brainstorm possible innovative solutions for transition in Northern Ontario.
- Procedure:** During the interview you will be asked to provide your comments and opinions in response to questions about primary care transition of youth with pediatric-onset disabilities, such as cerebral palsy from the pediatric to adult health care system. This study is interested in such things as transition barriers experienced by both pediatric and adult primary care physicians, especially in Northern Ontario. The study is also interested in identifying possible innovative solutions to transition barriers.
- The interview will last approximately 30 minutes, and will focus on discussion of the current care plans and primary care processes for youth with Cerebral Palsy in Sault Ste. Marie, any barriers to transitioning youth from pediatric to adult primary care, and possible innovative solutions to assist in smooth transitions to adult health care. The sessions will be audio recorded to ensure data accuracy.
- Confidentiality:** All information will be kept confidential. The researcher will transcribe the discussion from the audio recording and only the researcher (Chelsea Seguin) and her supervisor (Dr. Nicole Yantzi) will have access to the original data. Your comments in discussion will only be identified by your medical specialty (i.e. pediatrician or family physician). All identifying information will be removed from the written transcripts. Any reports of this research will not identify you or anyone whose name you mention. All data collected will be secured in a locked filing cabinet on a password protected USB drive for a period of five years following the interview.
- Benefits/Risks:** There are no direct benefits or risks to you or your patients in participating in this interview, except that you may appreciate being given the opportunity to express your views. In so doing, you will help the researcher to identify an unexplored area of research (medical transition in Northern Ontario) that will be truly informative and helpful for Ontario physicians and young adults with cerebral palsy. The results formulated from this study have great potential for knowledge translation across the medical community.

I have read this statement and I agree to participate in this interview. I understand that I am free to withdraw at any time without any consequence to me.

I understand that I may contact the facilitator/researcher, Chelsea Seguin at the Laurentian University email address, cseguin2@laurentian.ca, at any time if I have questions about the study.

I understand that I may contact the Laurentian University Ethics office regarding possible ethical issues or complaints about the research itself. The ethics officer may be reached at ethics@laurentian.ca

Name: _____

Witness Name: _____

Signature: _____

Signature: _____

Date: _____

Date: _____

Supplementary Consent for Use of Collected Interview Data

Interview Discussion of Master's Thesis for Primary Care Physicians entitled

"Understanding the Primary Health Care Transition of Youth with Cerebral Palsy from the Perspectives of Pediatricians and Family Physicians in a Northern Ontario Community"

1. I agree that this interview may be audio recorded. YES NO

2. I agree that that direct quotations may be used from our recorded interview without the researcher (Chelsea Seguin) receiving direct permission. YES NO

If NO, I agree that the researcher (Chelsea Seguin) may reach me at the contact route provided below to obtain permission for direct quotations. YES NO

Contact Information: Email: _____
 Tel: _____

I have read and understand the above statements.

I understand that I may contact the facilitator/researcher, Chelsea Seguin at the Laurentian University email address, cseguin2@laurentian.ca, at any time if I have questions about the study.

I understand that I may contact the Laurentian University Ethics office regarding possible ethical issues or complaints about the research itself. The ethics officer may be reached at ethics@laurentian.ca.

Name: _____

Witness Name: _____

Signature: _____

Signature: _____

Date: _____

Date: _____

Appendix H: Semi-Structured Interview Script



Understanding the Primary Health Care Transition of Youth with Cerebral Palsy from the Perspectives of Pediatricians and Family Physicians in a Northern Ontario Community
Chelsea Seguin, Master's Candidate, Interdisciplinary Human Development

Interview Script Questions

1. Describe your practice to me:

PROMPTS:

- ☐ How many patients do you have?
- ☐ Can you describe the average age range? Do you have a young population, older?
- ☐ How long have you been practicing in Sault Ste. Marie?

2. Do you have experience treating or caring for patients with Cerebral Palsy (CP)?

PROMPTS:

- ☐ What were the age ranges of your CP patients?

3. Describe what a typical care process might be for a person with Cerebral Palsy (CP) in Sault Ste. Marie from diagnosis (infancy) into adulthood.

PROMPTS:

- ☐ Are there different patterns of care? Why? (i.e. severity of disability)
- ☐ What is unique about Sault Ste. Marie in terms of these patterns?
- ☐ Are they different than Southern Ontario communities?
- ☐ Describe critical transition points throughout this process.
- ☐ What are the benefits to the model/processes used in Sault Ste. Marie?
- ☐ What are the barriers/disadvantages to the model/process used in Sault Ste. Marie?

4. Describe the challenges in ensuring young adults with CP receive age appropriate primary care in Sault Ste. Marie.

PROMPTS:

- ☐ Which of these challenges do you think are specific to Sault Ste. Marie? Why?
- ☐ Describe the consulting communication between family medicine and medical specialties in Sault Ste. Marie.

5. What solutions can you think of that might close the transition gap for youth with CP from pediatric to adult care?

PROMPTS:

- ☐ Are there transition programs in Sault Ste. Marie?
 - o Yes – Describe.
 - How long have they been in existence?
 - What process was used to establish the program?
 - o No – Why not?
- ☐ How do you think provider toolkits/checklists/resources would benefit physicians in providing streamline care?
 - o Describe what the ultimate toolkit or care plan would entail.
- ☐ Institutional Solutions:
 - o Are you aware of the College of Family Physicians of Canada (CFPC) Section of Family Physicians with Special Interest or Focused Practice (SIFP)?
 - No – *Describe Program to Participant*
 - Yes (and No, after description) – Describe the benefits/disadvantages of this program
 - o Is the SIFP something you would consider signing up for? Why?

6. What else do you require that would help you to provide a successful transition?

7. Is there anything you would like to discuss that has not already been mentioned?